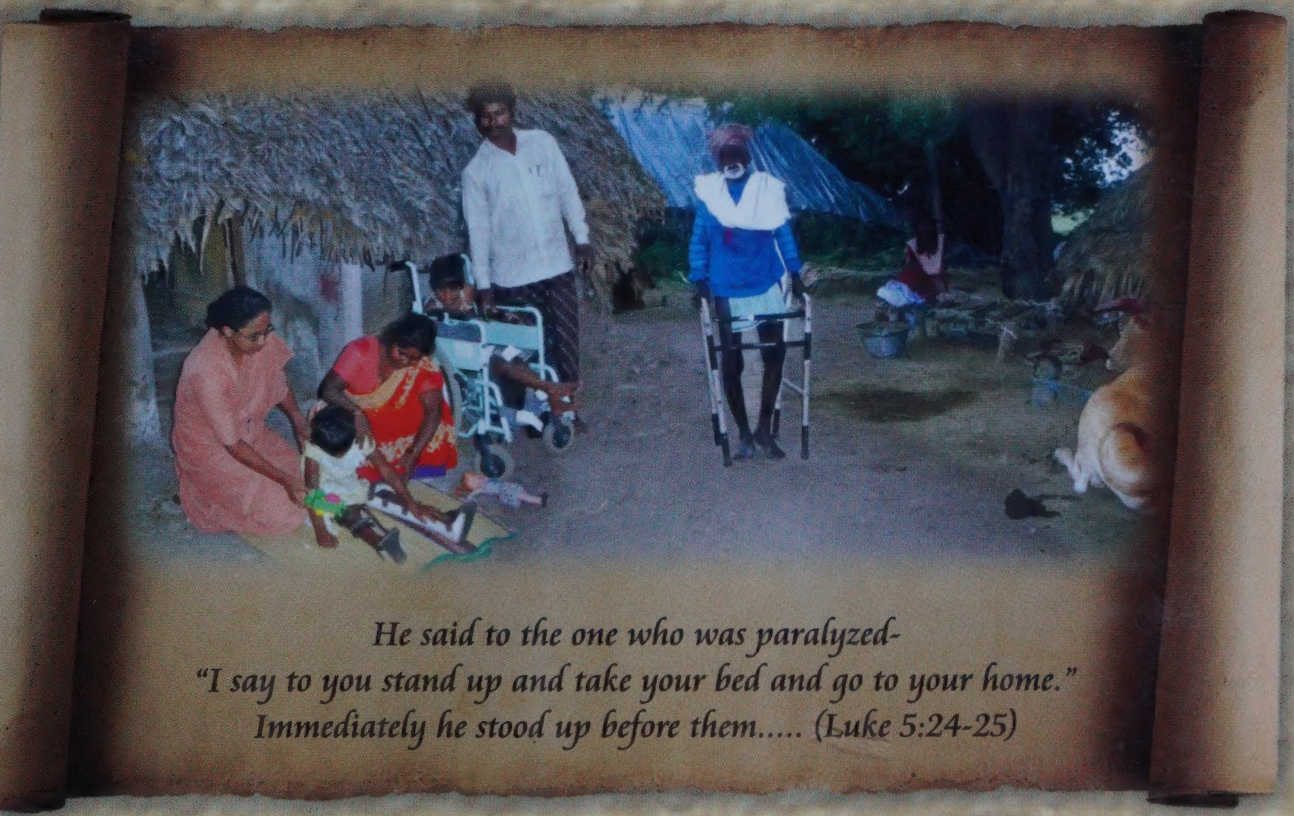
HEALTH FOR ALL

A RIGHT AND A POSSIBILITY



He said to the one who was paralyzed-
"I say to you stand up and take your bed and go to your home."
Immediately he stood up before them..... (Luke 5:24-25)

My Journey with People at the Periphery

Sister M. Agnesita AC

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Lovingly Dedicated
To
Mother Veronica of the Passion
(1823- 1906)
Founder of the Apostolic Carmel

Doing the will of God was her passion.
The need of the people defined her mission.
The poor and orphans, she considered her treasure.

God of sincerity,
you are offended by empty worship.
Let our hands which clap
be used to give .
Let our voices which sing
be used to comfort and encourage.
Let our feet which dance
never tire in helping the weary.
Let us not multiply our words
nor display our piety.
With due discretion let us
"comfort the afflicted
and afflict the comfortable."Amen.

J. Massyngbaerde Ford

CONTENTS

ACKNOWLEDGEMENTS

"Unless the Lord builds the house, the builders labour in vain." This verse of Psalm 127 expresses my usual sentiment, whether it is in writing this book, or at any other task or mission that is entrusted to me. The Lord guided me in very tangible ways in the process of writing this book. Even so, writing this book would not have been possible, if I were not supported by a circle of friends and family members.

Bishop Percival Fernadez readily agreed to write the foreword for the book, and I am immensely thankful for this gesture of his. I am grateful to my Congregation for nurturing me, both in my spiritual and professional life. Sister Agatha Mary A.C., the Superior General was happy that I was writing this book, and wrote a meaningful message. The members of the Generalate Team of the Congregation, who are my colleagues were there, sometimes to read through what I wrote, and always to encourage me in the process. I appreciate the support that I received from Sister Agatha Mary and the rest of the team members.

Sister Carol A.C. deserves a large share of my gratitude, because she patiently and painstakingly edited the book. I, being a novice in the art of writing, know for sure that it was not an easy job for her. May God bless you and reward you, dear Sister Carol. Sisters Vincenza A.C.and Carmilla A.C. have been a valuable support for me. They read the draft of the book, offered corrections and positive feedback. I am grateful to both of you dear sisters for giving me the push that I very much needed. Sister Violita A.C. readily agreed to do the tedious task of proof reading. Thank you dear Sister for your good will.

It was Fr. P. B. Martin who critiqued my work and offered helpful suggestions all along. If it were not for his help, the publication of this book would not have been possible. Dr. Ravi Narayan, who is an internationally acclaimed Community Health Advisor, and Dr. Sister Lucian SCC, the President of Sister Doctors Forum of India, were spontaneous in their appreciation of this work, and willingly took time off their many projects and works to review the book. Dr. Maya Thomas, an expert in the field of disability, gave her valuable suggestions for the chapters on disability. I express my heartfelt gratitude to all of you dear friends. May God bless you and your families.

Finally, I thank my brothers, who are also my friends and benefactors. I could rely on them in moments of trouble and problems. They were with me in the process of writing this book and gave some pertinent and professional advice. All of them took a keen interest in my work for the sick, the poor and the downtrodden. May divine blessings rest on all of us.

I cannot end this long list of friends without mentioning the publishers, Gujarat Sahitya Prakash. Thank you dear Fr. Jerry Sequeira SJ and team for your efficient services.

What They Say ...

As I read and re-read the pages of Dr. Sister Agnesita's book, "Health for All: A Right and A Possibility", I was reminded of the words of Prophet Isaiah, quoted by Christ at the beginning of his public ministry, "The Spirit of the Lord is upon me ,because he has anointed me to bring glad tidings to the poor. He has sent me to proclaim liberty to captives and recovery of sight to the blind, to let the oppressed go free, and to proclaim a year acceptable to the Lord."(Luke. 4: 18-19). Sister Agnesita's book, with its 15 chapters speaks of the comprehensive health ministry that she organized, and her work for the liberation of the Dalits and other marginalized groups, in particular of women, in and around the 100 and more villages of Chengalpattu District, Tamil Nadu and Nilambur *Taluk*, Kerala, as also her work with alcoholics in the slums of Bangalore. The book is her lifetime mission experience. Sister Agnesita has inserted some aspects of theory as well as certain statistical facts, in order to draw the attention of the readers to the gravity of the issues, that are discussed in the book. She gives plenty of useful information and provides practical guidelines for social action. This book is bound to inspire and challenge many of us to be pro-poor and pro-oppressed activists.

Reading this book has been for me an education, an inspiration and a spiritual experience. I am sure many of the readers will have a similar experience and resonate with the ideas and sentiments expressed in the book.

Sister Agatha Mary A.C., Superior General
Apostolic Carmel , Bangalore -560041

"Health is a social, economic and political issue and above all a fundamental human right. Inequality, poverty, exploitation, violence and injustice are at the door of ill-health and the deaths of poor and marginalized people."(The Global People's Charter for Health.)

Sr. Dr. Agnesita A.C. has fought a good fight, to make Health for all a Right and a Possibility by her prophetic and proactive presence and service among the exploited and the less privileged in accordance with the signs of the times and the values of the Gospel.

May this slim volume of her rich experiences, inspire, enthuse and energize every committed healer to reach out to the unreached with health and wholeness.

Sr. Dr. Lucian SCC,
President,
Sister Doctors Forum of India.

This compilation of reflective chapters by Dr. Sr. Agnesita, building on her rich experience of community health, over many decades is an excellent introduction to the social, economic, political, cultural, and environmental determinants of health, which are at the core of public health and community health action today.

In 2000 AD, The Global People's Charter for Health had outlined in its preamble that **"inequality, poverty, exploitation, violence and injustice are at the root of ill health and the deaths of poor and marginalized people".** Dr. Sr. Agnesita's reflections are a very good contribution to this assertion.

Through very moving stories and case studies she has brought together a deep humanism and a professional perspective that is willing to go beyond the bio-medicalized hospital model. Starting with the idea of a hospital without beds, she moves very effortlessly to a whole range of interesting and grounded

challenges, whether it is snakestones, herbal medicines, traditional healers, alternative system of medicines, or social challenges like the caste system, poverty, starvation, and social exclusion. These are the challenging mosaic of community health problems. Her book also deals with solutions, simply stated and practised with sincerity, whether these are, training local health workers, organizing women, building self help groups or *sanghas*, tackling livelihood options and building communities. She also effortlessly widens the range of community health challenges to look at people with disabilities; the challenges of mental health; the degrading features of urban slum life and the challenges of a state, preoccupied, not with health but with a population paradigm.

Ultimately Dr. Sr. Agnesita succeeds in outlining the crux of a new community health approach that is woven together with rights, gender sensitivity, community responsibility, collective action, and above all hope and commitment. Animated with interesting quotations from a wide variety of sources, the book becomes a primer of community health, written in an engaging story and case study format that illuminates and inspires. I would recommend this book to all those who wish to become fellow travellers on the long road to 'Health for All'. For those who are already on this journey the booklet will be an invitation to reflect and recharge one's battery to continue the journey.

Dr. Ravi Narayan
Community Health Advisor,
SOCIETY FOR COMMUNITY HEALTH, AWARENESS,
RESEARCH AND ACTION (SOCHARA),
Bangalore.

Foreword

I most willingly agreed to write this FOREWORD to Dr. Sr. Agnesita's well-researched and down-to-earth product of love and concern, for the health care of most of the people in our beloved country! This work could only be the result of a deep conviction, that we are yet a very long way from making health care accessible to most of our brothers and sisters, living in the far-flung areas of our country.

Indeed, as Dr. Sr. Agnesita rightly puts it, ours is ONE COUNTRY but TWO INDIAS! To realize this fact one has only to look at the modern, well equipped, super-specialty hospitals coming up one after the other in cities like Delhi, Mumbai, Hyderabad, Chennai and Kochi, catering to the minority of our people, and made inaccessible to most who cannot afford it, even if they lived in these cities. The majority of our people, who live in distant villages have to manage with meagrely equipped health care facilities if there are any in the vicinity.

Recently I had a call from a Doctor Religious Sister, trained by St. John's Medical College in Bangalore, now working in a remote village in Arunachal Pradesh, bordering China. She had to travel 18 hours to be able to call me over the phone! Such facilities are not available in the area she renders her health care services. One can imagine what else is available for the people living in that area, completely forgotten by those in power!

I am grateful to Dr. Sr. Agnesita for venturing into writing "Health

For All: A Right And A Possibility", to highlight the woefully inadequate and misplaced health care facilities in our country. Her contention that something can be done in this area OUT OF NOTHING is so true. All that is required is good will and concern. The rest will fall in place.

In the late 1970s, The Catholic Bishops' Conference of India, realizing the urgent need to have doctors in the remote areas of our country, made Rural Service by Doctors, graduating from St. John's Medical College, one of the main objectives of the College. In order to ensure that this objective is achieved, the College reserved 25% of the MBBS seats for Religious Sisters, who function in some of the medically most neglected areas of our country. As a result today over 500 Religious Doctor Sisters are out there in areas where people, who are forgotten by the powers that be, have to travel long distances to reach a poorly equipped public health care facility.

Yes, as Mother Teresa rightly said "We should never worry about numbers. Help one person at a time and always start with the person nearest you." Thank you dear doctors and nurses, working for our people that need you most! Thank you for your correct priorities in the health care ministry: Not specialization in medical sciences to help a few living in comfort, but with sufficient medical knowledge to be near to your brothers and sisters, who can neither reach nor afford sophisticated health care, but are in search of basic care to keep themselves healthy. May God reward your selfless commitment, for he has said, that 'as long as you did it to the least of my brethren, you did it to me'! (Mathew 25:40)

+ Percival

Bishop Percival Fernandez

Emeritus Auxiliary Bishop of Bombay

First Director of St. John's National Academy of Health Sciences, Bangalore

April 21, 2012

Introduction

What has a medical practitioner to do with the caste system, Dalits and the poor? These ignorant people, with their superstitious beliefs are hard to convert to rational, hygienic and healthy practices. Why waste our lives with these drunken and dirty people? This sounds very much true. Three decades ago, I would not have imagined that I would have to do anything with these people. Then I walked right into the life situation, so to say of these people. Then everything changed.

Fortunately, there was neither a beaten track nor a traditional mould for me to follow. In fact the oft heard chorus was, "What will you do in a congregation that is mainly devoted to education?" I did not have any answer. Neither was I anxious. I knew that it was the Lord's doing and that he would provide the answer. He did provide and that too in strange ways, that only he could accomplish. It was a simple way, yet it was a path with many twists and turns. I had only to follow the path that he was opening before me.

My faith was firmly rooted in the Christian belief, that all human beings were created in the image and likeness of God. I could not but treat every human being, whether a woman or a man, poor or rich, old or young as of equal dignity and worth. In my formative years as a religious sister, I had the opportunity to delve deeper into the Old Testament and New Testament writings. Yahweh, who walked with his people, and who was ever sensitive to the cry of the poor and the oppressed, had

touched my heart. Jesus of the Gospels challenged me, and he was my inspiration and model. I was happy that Jesus, who called Peter the fisherman, Matthew, the tax collector and Judas the betrayer, also called women to be his co-ministers, together with men. Finally, the scene of washing of the feet of the disciples by Jesus, is the concrete demonstration of equality of status of human beings. In his Kingdom, there is no place for hierarchical differences between master and servant; high and low, rich and poor. The privilege of official or professional authority is to serve the suffering and the needy. This particular episode ends with the injunction of our Master and Lord Jesus, "You also should wash one another's feet."

Human rights are a natural sequel to the concept of equality and dignity of human beings. The Church therefore, in the words of Pope John XXIII in *'Pacem in Terris'*, affirmed that "every human being has the right to life, to bodily integrity, and to means which are suitable for the proper development of life; these are primarily food, clothing, shelter, medical care and finally the necessary social services." The Second Vatican Council, in its 'Pastoral Constitution on the Church in the Modern world', reiterated the theme of human rights in the following statement: "With respect to the fundamental rights of the person, every type of discrimination, whether social or cultural, whether based on sex, race, colour, social condition, language or religion, is to be overcome and eradicated as contrary to God's intent." (No.29)

Health is one of the fundamental rights of human beings. The preamble of The Constitution of The World Health Organization states that, "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being, without distinction of race, religion, and political belief, economic or social condition." The article 25 of The Universal Declaration of Human Rights also recognized health as one of the fundamental human rights.

In 2005, The Catholic Bishops' Conference of India published the Health Policy of the Catholic Church in India, titled 'Sharing the Fullness of Life'. The Mission Statement of this policy is formulated thus: "to provide humanizing care considering the dignity of the person and the needs of the society; to ensure promotive, preventive, curative and rehabilitative health care to all, particularly to the poor and the marginalised through their empowerment; to engage in social mobilisation of the community by creating awareness on rights, duties and responsibilities related to health issues." This Health Policy, under its guiding principles further states that, "The interventions of the Church will be guided by Article 25 of The Universal Declaration of Human Rights, that says that all have the right to a standard of living, adequate for the health and well-being of themselves and their families."

It is true that I did not have a blue print for my course of action, but I had certain aspirations and dreams. I was convinced that the poor and the neglected had a right to my service. The 1970s and 80s were the years when the Church all over the world, including the Church in India, spoke of the 'option for the poor' as a sure way to follow Christ the Lord. I knew I was on the right path. The circumstances in which I was placed, and the exposure I received by living in close contact with the poor and the lowly, all contributed to my learning, the harsh realities of the lives of people living in abject socio-economic conditions.

If health is a right then it must be accessible, available and affordable to all. The World Health Organization held its first International Conference on Primary Health Care in Alma Ata, former USSR in September 1978. "An acceptable level of health for all the people of the world by the year 2000", was the call given by Alma Ata Conference. Representatives from 134 countries, including India signed the Alma Ata Declaration, which affirmed that health was a fundamental human right and that primary

health care was the only way to attain 'Health For All by 2000.' Since a large majority of the world population still did not enjoy 'Health for All' status, in 1998, the World Community once again signed The World Health Declaration, "Health For All in the 21st Century." The World Health Organization urged and continues to urge its member nations, not to give up the ideal of 'Health For All' but to strive to make it a reality for their people.

As an individual, my energy and resources were limited. I decided to make people active partners in the community health programme. This is the secret of success of my story, which I share through the pages of this book. This book is not the result of a research work, but it is the fruit of my search to make 'Health for All' a possibility, because health is their basic right. This is my story; my story entwined with the stories of the sisters of my congregation, the stories of people with whom I worked and people who helped me to carry forward my vision; the stories of the patients whom I treated, and above all the stories of the village women, who dared to break away their shackles of slavery and oppression.

I acknowledge, that there are many heroic persons who have sacrificed their lives for the cause of social justice. Among them are Sisters Rani Maria FCC and Valsa John SCJM. I bow my head to them in admiration and appreciation for their dedication and commitment to the cause of the poor. Many of us might not be called to such a heroic degree of commitment. Yet, any work for the oppressed and downtrodden is sure to bring with it a series of challenges, failures and disappointments. There was a heavy downpour of these problems on and off in my life. However, the predominant memory that pervades my life is one of gratitude to God, who provided these opportunities to be of service to his 'little ones'.

The purpose of my writing this book, is to share with the readers my conviction, that there is more joy in giving to the needy and

deserving than to the greedy and demanding; there is more satisfaction in serving the least and the last, than the rich and the powerful; there is more happiness in loving those who cannot repay our love, than loving those who shower on us flattery and fame. After all Jesus' categorical statement is undoubtedly addressed to each one of us, "I tell you the truth, when you did it to one of the least of these my brothers and sisters, you did it to me."

Even if a small number of readers of this book find encouragement to stay on in their chosen ministries, for the poor and downtrodden, it would fulfil my objective of writing this book. Further, my hope is that the book will be a motivator, and a resource book for anyone who desires to launch into the difficult, but challenging ministries of working with the marginalized and downtrodden, whether it is education, healing ministry or social action.

Sister M. Agnesita AC

1. Small Is Beautiful

Let the little children come to me; do not stop them; for it is to such as these that the kingdom of God belongs.
(Mark 10:14)

There was a knock at the door. I looked at my wrist watch. It was 7 p.m. It was dark outside and raining heavily. There was the knock again; this time it sounded desperate. I opened the door. It was a strange sight. A man, wet and shivering to the marrow, carried a woman on his shoulder. "She is my wife, Shanthi. She is very sick," he explained, with fear in his eyes. He was so famished, that I thought he would faint any moment. "Someone in the village told me that there is a hospital in Palliagaram, and, the sisters would save my wife."

I had joined our community at Palliagaram just a few months before. Unlike other Apostolic Carmel communities, this recent foundation had no school attached to it; instead, our sisters had been running a small health centre here for the last two years. They were happy, that at last I had arrived to take over the responsibility of the health centre. It was the year 1977.

Palliagaram is about fifteen kilometres from Chengalpattu town and seventy kilometres south of Chennai. For people, this was a hospital, but in reality it was a health centre and a small one at that. The health centre was just a two-roomed building. The

main room had been partitioned off to serve different purposes, such as, consultation and examination of the patients, dispensing medicines and dressing of wounds and for injections. After I took over the responsibility of the centre, the dressing room served also as a minor operation theatre and labour room. The second room served as pharmacy as well as storeroom.

From the time I had entered the medical college, I had a desire to serve in the rural areas and render medical service to the poor. On an earlier occasion, when I had visited the sisters in this place, I had instantly felt that I belonged here. I dreamt of the day when I would be free to spend my life in the midst of the people of this area.

I was not, however, prepared for the things that I saw and experienced at the health centre. I looked at the man almost angrily, and asked him why he had delayed to bring his wife. "We are from Mallikapuram village, twenty five kilometers from here," he said. Then he gave me the history of Shanthi's illness. Shanthi was 23 years old and they had two small children. For some months, she had been suffering from excessive menstrual bleeding. Like any mother from a poor family, she had no time to think of her own health problems. She continued to work hard until she collapsed with breathlessness and exhaustion. He and the other members of the family were desperate, and feared for her life. That evening, they took her to a close by nursing home, where the doctor admitted her and gave her some injections. Her haemoglobin level was less than 2gm/dl, the doctor there told them. "We do not understand what this means.", he said. Next morning, they were given a bill for Rs.3,000/-. They pawned the few small things they had in their house and paid the bill. They requested the doctor to discharge Shanthi, as they could not afford to pay any more money. The doctor was upset and angry, and discharged the patient against medical advice. Fortunately, someone gave the husband information about Palliagaram. He

carried Shanthi on his shoulders, got into a bus and came straight to our health centre. "Please do not send us anywhere else," he pleaded. Shanthi, who was finding it difficult to breathe, managed to make herself audible: "I am ready to die here."

Such daily encounters with patients, who had many more pathetic stories to tell, made me realize that these were not isolated cases, but were symptoms of a widespread malady of neglect of the health care of the rural poor. Here, in our health centre I had to see about two hundred patients everyday, who suffered from all types of illnesses. The people were so poor, that they could not afford investigations and even the minimal cost of treatment. I had to rely solely on my clinical judgment. Fortunately, during the days of our medical education, insistence was more on clinical diagnosis than on investigations. Investigation was only there to confirm what you already had suspected and diagnosed. Even then, how could I initiate treatment for tuberculosis and other lower respiratory tract infections without even a chest X-ray? How could I treat a patient like Shanthi, with haemoglobin level as low as 2gm/dl without blood transfusion? Chengalpattu District Medical College Hospital was only 15 Kms away. However, most of the patients refused to go there on referral, because of the callous attitude of the doctors and other staff towards these illiterate and poor patients.

One Country, Two Indias

India has trained the world's second largest pool of scientists and engineers, while about 30% of Indians are still illiterate. "During the course of this year, the number of US dollar billionaires in India doubled to 69, holding combined assets, the equivalent of one-third of the country's GDP[1]", while about 500 million Indians

[1] John Dayal, "An Agenda with a Vision", *Indian Currents*, Vol. XXIV, No.02,(2012):p.28.

live below the poverty line. India is on the verge of privatizing water supplies, whereas about 20 million people of our country do not have access to safe drinking water. India is one of the nuclear powers of the world, but only 31% of our population has access to improved sanitation facilities.[2]

India is promoting medical tourism and supplies doctors to foreign countries. India, with its state-of–the-art medical facilities, is attracting patients worldwide. The number of foreign nationals, seeking specialized high cost surgery, and other treatments in Indian hospitals is on the increase. Super specialization hospitals are mushrooming in cities like Chennai, Bangalore, Hyderabad, Mumbai and Delhi. In Chennai alone, twenty hospitals offer renal transplant services.

On the other hand, India carries a high percentage of global burden of infectious diseases. India accounts for nearly one third of the global burden of tuberculosis. India alone represents 64% of leprosy prevalence and 78% of new case detection worldwide.[3] The same is true of other diseases, such as, malaria, acute respiratory illnesses and diarrhoeal diseases.[4] More than 75% of doctors are based in cities, whereas about 70% of patients in this country are village-based. Even though there is a Government Primary Health Care Centre (PHC)for a population of 30,000 in rural areas, studies on the functioning of PHCs show that absenteeism of doctors is very high. About 20% of sanctioned posts of the doctors for the PHCS are not filled. When these

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2 "Joint Monitoring Programme for Water Supply and Sanitation Estimate for 2008" based on the 2006 Demographic and Health Survey. UNICEF/ WHO http://en.wikipedia.org/wiki/water_supply_and sanitation_in_india

3 K.Park, *Parks' Textbook of Preventive and Social Medicine*, 18th ed. Jabalpur: Banarsidas Bhanot, 2005, p.253.

4 NCMH Background Papers-"Burden of Diseases in India", (On line) New Delhi: National Commission on Macroeconomics and Health and Ministry of Health and Family Welfare, Govt. of India, 2005,p.2.

factors are taken into account, the doctor-patient ratio in rural areas is as low as 1:34,000. When we compare this with the doctor-patient ratio in Delhi, which is 1:472, and the national average of 1:1,676, we can understand the dismal situation of health care in remote villages.

People seeking health care from PHCs, are often treated by paramedical staff. Moreover, people have to walk long distances to reach PHCs, only to be told that no staff is available there to attend to their needs. Non-availability of drugs is another problem. Many of the essential drugs are not available in government health centres. The patients are only given a prescription and the people are forced to buy medicines from outside medical stores. Is it any wonder then, that Shanthi and her family had to seek private medical care, even though they could not afford it?

Small is Homely and Accessible

It was a hopeless situation. The desperate and pleading eyes of Shanthi settled the matter. Against all reasoning and common sense, I decided to keep her and treat her at the health centre. I gave her a mat to lie on. This simple act of acceptance and assurance calmed Shanthi and her family. I started her on a high protein diet and iron injections. People had great faith in the packet of 'flour mix' that I was advertising, instead of tonics, that the doctors usually prescribed. The simple ingredients of ragi, wheat, groundnuts, green gram and jaggery made it very nourishing. Except for wheat, other cereals and pulses were locally cultivated. This 'flour mix' was ideal for Shanthi. The relatives looked after her. They would make porridge of the 'flour mix', and feed her in small quantities, until her appetite improved and she regained her digestive capacity. Gradually, an egg was added to her diet. Meanwhile, her menstrual problems had been treated. Within ten days, Shanthi was able to walk about and was ready to go home.

Now you may wonder where, in this two-room health centre, Shanthi was admitted. In fact, our health centre was, from its inception, a twenty-four hour service centre. Patients with major road accidents, women in difficult child birth, persons who had attempted suicide, patients with snakebite and people with sudden onset of any illness would be brought in at any part of the day or night. No patient was ever refused, however serious the problem might be, and however poor the patient was. The patients who needed specialized care and major surgery were, of course, referred to Chengalpattu Medical College Hospital.

Seeing this situation, people naturally asked me, "Sister, why don't you start a hospital like that of ... (they would mention the names of the hospitals run by different religious congregations.)?" "Will you be able to pay for the bed and all the services that would be entailed in that?" I asked them. They had not thought of the cost factor and they would be silent. Not only lay people, but priests and religious were also wondering why I was struggling with this small health centre. "Why are you wasting your life in this remote village," was the question asked by many.

A Big Hospital, to What Purpose?

I knew that people would flock to our hospital if only I began one. The health centre was situated close to the state high way, and people from a distance of 60-70 kilometres were coming for treatment. People had a tremendous confidence in our diagnosis and treatment. Funds would come easily for construction of a rural hospital. Equipping the hospital was not a problem either. I visualized a medium-sized general hospital, well equipped with essential diagnostic facilities of laboratory and X-ray departments, and other supportive facilities. Nevertheless, I was confused. In my new role of the doctor and administrator of the hospital, will I have time to interact with the patients, and understand their problems and needs? Rather, will I not be a doctor in the white

coat, far removed from the actual milieu of patients? More than anything else, I was thinking of how the proposed hospital would affect the financial and social profile of the patients.

The health centre gate was open to anyone in need of medical care. There were no security personnel at the gate to check or to stop any one. They could walk in at any time of the day or night. The treatment would cost them only a few rupees. Those who could not afford even this, would come with some groundnuts or rice, which they had received as part of their daily wages. The health centre had a homely atmosphere. People, however poor they were, did not hesitate to come to us with their health problems.

Will the people be able to walk into the proposed hospital with a few rupee coins in their hands? Will not my big, posh hospital with its closed gates, frighten these poor simple people? A hospital with its different departments needs professional staff. The salary of the staff, and other recurrent expenses like purchase of medicines, maintenance of equipment etc. need finances. So, only people, who can pay some decent amount of money will be able to make use of our health services, and not people with empty purses and empty stomachs.

A Hospital without Beds

At this point, I woke out of my reverie. With a District Medical College Hospital only 15 kms away, I was convinced that I did not need to start another hospital. People were used to sleeping on mats, and sleeping out in the open was not strange to them either. At night, they would sleep wherever they could find some space in the two rooms of the health centre. During the day, the space was needed for the overcrowded outpatient services. Providentially, we had two large shady neem trees. Those who were quite ill would lie down inside, but those who were able to

walk about would rest under the trees. The relatives, with their keen eyes of observation and love in their hearts were the best care givers.

With all the basic facilities available for handling emergency situations, we were available to patients at any time. We accepted even suicidal and accident cases, as well as victims of domestic and communal violence, knowing full well that these were medico-legal cases. Once the life-threatening situation was under control, they had time to go to the government hospitals, get further treatment and register the case and so on. I was there to save the lives of people and they were grateful for this service. Very often, the police accompanied the people, so that I would not hesitate to treat these patients.

Moreover, the rational drug therapy was the policy at our health centre. Generic medicines without combinations were prescribed. We made sure that only the essential drugs that were needed to cure the disease were given to the patients. It meant at times, keeping the patient at the centre without any additional cost to them, for observation and care. We had to explain patiently why, unlike some of the private practitioners, we did not start intravenous fluids for every patient who was admitted. The practice of the rational drug therapy, kept the cost of treatment low and affordable to the people.

It is a usual practice that doctors prescribe a long list of medicines, in the hope that the patient would be happy with their expertise. The most over prescribed drugs are antibiotics(antimicrobials) and steroids. Antibiotics, when discovered in the 1940s, were a life saving drug. Inappropriate use and overuse of these drugs is causing a dangerous trend. The organisms are becoming resistant to many of the antimicrobials. This is a major concern because the resistant organism can kill, and also cause a financial burden on the patients. When the micro-organisms become resistant to most antimicrobials they are referred to as "superbugs". No

wonder The World Health Organization chose the theme for World Health Day, 2011, 'Antimicrobial resistance: no action today, no cure tomorrow'.

Thus, this small rural health centre, with its open gates, was a welcome place for patients from Dalit and tribal communities. Its very smallness made it accessible and available to people at all times. The utilization pattern of our services showed that 60% of patients were Dalit women. These shy, silent suffering women found a place, where they could freely express their fears and clear their doubts and get the right treatment. They did not need to hide their health problems any longer.

Slowly my anxieties subsided, and my doubts vanished. Here was an opportunity to be of service to the 'little ones', of whom Jesus spoke. The emergency cases and unexpected situations constantly challenged me. The wide variety of problems that I encountered motivated me to update my knowledge, both in medicine and on wider issues of social and cultural concerns. I was learning fast what ill health meant for the poor and exploited people.

> I am not sure exactly what heaven will be like, but I know that when we die and it comes time for God to judge us, he will not ask, 'How many good things have you done in your life?' rather he will ask, 'How much love did you put into what you did?
>
> *Mother Teresa*

2. Snakebite, a Neglected Public Health Problem

All in the crowds were trying to touch him, for power came out from him and healed all of them. (Luke 6: 19)

It was midnight. There was loud wailing and cries from a whole crowd of people. It was nothing new to be woken up at any part of the night, by the shouts and noise of people coming to the health centre. However, this was different. To my surprise, our neighbours were also among the crowd. People were beating their chests and crying loudly as at a funeral procession.

A girl of about fifteen, Lalitha, had been bitten by a snake. As I was attending on her and giving her first aid treatment, I asked them why they were crying when the girl looked so well and healthy. They had killed the snake and brought it along with them, so that we could see that it was a poisonous snake. The snake was a krait. For a krait bite, there was usually no cure, they told me. I did not want to take any chance. Our ambulance and the driver were always ready for any emergency. Immediately, Lalitha was sent with her family to the medical college. The other people who had gathered at the health centre told me, that the girl would die early next morning. That was exactly what happened. In spite of the antivenom treatment, she died by 9 a.m. the next day in the hospital.

Snakebite Deaths, a Neglected Health Problem

Snakebites are the common cause of morbidity and mortality in tropical countries like India. Of 216 species of snakes found in India, only four species are venomous, viz. cobra, krait, Russell's viper and saw scaled viper. Studies on venomous species of snakes in different states of India showed that, in Tamil Nadu, the cobra and the krait were the most commonly found poisonous snakes. It is estimated that, on an average, nearly 2,50,000 persons fall prey to snakebite per year. There are no precise data available regarding the exact number of people dying annually from snakebite. According to some studies, about 50,000 of them die every year. In fact, as many people die of snakebite in India, as in the rest of the world put together.[1] Other studies indicate that the number may be as low as 20,000. In any case, the actual number of deaths from snakebite may be smaller, than the number of deaths occurring from diarrhoea and other infectious diseases. Perhaps due to this comparatively smaller number of deaths from snakebites, this problem is not taken seriously. "The deaths and suffering from venomous snakebites remain largely invisible to the global health community. In the 21st century, snakebite is the most neglected of all the neglected tropical diseases," said David Warrell from the University of Oxford.

Snakebite is an occupational health hazard to farmers and daily labourers in rural areas. Young people are bitten by snakes when they work in the agricultural fields. Epidemiological studies show that the peak age group of snakebite deaths is 15–29 years. Thus, it is usually the young, bread winners of families, who die of snakebite. Antivenom is not easily available and accessible to people. Sometimes, it takes 5-6 hours for the patient to reach a health facility, where the antivenom is available, and then it is

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[1] John Sudworth , "India's Battle Against Snakebites" (on-line), Delhi: BBC Correspondent), 2006.

usually too late. Even if the person is lucky to reach a hospital in time, the antivenom may not save everyone.

Cobra and viper bite may produce pain and swelling, and so the person bitten is usually aware of the snakebite. The krait bite is much less obvious and it is very difficult for people to know that they have been bitten at all. These bites usually occur at night and are not associated with pain, and or any other symptoms. For these reasons, the krait bite is more often fatal than bites from the other three of the venomous species of snakes. The poor are affected more than the rich, because they have only huts and hovels, without any safety of doors and secure walls or roofs. I am told that whole families in the villages have been wiped out, because this particular snake creeps into the huts at night and bites people in their sleep. In the morning, the neighbours find them dead.

This knowledge of common people is corroborated by recent documents released by both The Government of Tamil Nadu and The World Health Organization.

> The Common Krait is a nocturnal (*night*) snake ... often seeks habitation near human dwellings. During the day it rests up in piles of bricks, rat burrows or other buildings. The Common Krait is the most poisonous snake in India.[2]
>
> Bites may be inflicted in the home by peri-domestic species such as cobras (*Naja*), which may live in roof spaces or under the floor, and by kraits (*Bungarus*), which enter human dwellings at night in search of their prey and may bite people in their sleep.[3]

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2 *Handbook on Treatment Guidelines for Snakebite and Scorpion Sting,* (Book online) Chennai: Tamil Nadu Health Systems Project, Health and Family Welfare Department, Government of Tamil Nadu, 2008. p.7

3 David A Warrell, *Guidelines for the Management of Snake Bite. Geneva:* World Health Organization,(2010). p.37.

Snake Stones – an Effective Therapy

I could not forget the face of the young girl who died of snakebite. Fortunately, a few days prior to this incident, I had read about the 'snake stone' and its curative properties in the monthly magazine, 'Health Action', published by The Catholic Hospital Association of India. My allopathic trained mind had not given a second thought to this particular write-up, but now that allopathic medicine had failed in this case, I searched for the article and read it again and again. Fortunately, the write-up also gave the address of Fr. Antonius CMI, who supplied the stone. I did not lose time in meeting this venerable priest, who was at that time living in Calicut, Kerala. The priest, who was already 80 years old at the time, explained to me patiently all that I needed to know.

Actually, it was not a stone, but a medicine, processed from rare herbs and roots which were not easily available. For want of a better term, it was being termed 'snake stone'. It originated in Sri Lanka and the priest used to get the supply from that country. Unfortunately, from the time the internal war started in Sri Lanka, he could not get the supply of these valuable stones. Fr. Antonius was sad that people were dying of snakebite. "If I only had the snake stones I could have saved the lives of these young people", he kept saying to himself. His compassion for the people motivated him to try his utmost to secure the stone. The war situation was going from bad to worse, and he realized that it was impossible to get the stones from Sri Lanka.

Patience and perseverance are the key to success. His persistence was almost miraculously rewarded in a more fruitful way, than getting the ready -made stones. Through some friends, he was able to get the guarded secret of the composition and the ingredients of the stones, and the details of the process of making them. The collection of these herbs was an arduous task; he had to travel the length and breadth of the country, to

identify and collect these herbs and roots. The thought of the possibility of saving the lives of the patients gave him the energy and enthusiasm needed. Finally, he succeeded in making these 'precious stones'.

Fr. Antonius was not a person to be satisfied with just making these stones and marketing them. He wanted to be 100% sure of their pharmacological properties and effectiveness. Trivandrum Medical College was ready to collaborate in this venture. Their partnership resulted in elaborate scientific research and they recorded the stone's curative properties, the various enhancing and inhibiting factors, and other data. I was happy to read through all these painstakingly recorded documents. Now I had no doubt of the efficacy of this little stone. From Fr. Antonius, I also learnt the practical method of using these stones, but bias and prejudice die hard. My allopathic trained mind was not yet ready to use any other system of medicine.

Initially, I used the stones only to diagnose whether the bite was by a venomous snake or not. Every snakebite is not poisonous. So, the first step is to reassure the patient. If the bite was of a poisonous snake, the stone would adhere to the small, superficial incision made by the scalpel around the area of the snake bite. Sending the patient unnecessarily to the medical college increased their anxiety and also wasted their meagre resources.

Magical Herbal Medicine

Gradually, I gained confidence. We started treating the people, who came with venomous snakebites, in the health centre itself. Because of the dramatic effect, of these almost magical stones, I remember clearly the details of the first few cases I treated with the use of them. Murugan of Mangalam village was the first person on whom I decided to use these stones. While transplanting paddy in the field, he had felt a sharp pain on the tip of his index finger. As he withdrew his finger, he saw the cobra moving away

from him. The village was only about two kilometres away from the health centre. He ran as fast as he could to reach the centre. He was 24 years old. I made a superficial incision at the point of the bite and kept the snake stone there and, to my surprise, the stone stuck to the tip of the finger, and any amount of shaking of the finger did not dislodge the stone. I decided to continue his treatment in our health centre. I followed the procedure as taught by Fr.Antonius. Murugan went home after five days and had no after effects whatsoever.

The second person whom I treated was Arumugam from Palliagaram village. He was bitten by a krait on his right shoulder. Again, the stones adhered firmly to the shoulder region. We need to keep 5-8 stones at a time, and change the stones every 48 hours, until the stones stick to the incisions no longer. The used stones are cleansed by immersing them in milk for half an hour. The stones thus treated are washed and reused. Arumugam's family was utterly poor and could not afford to pay any money. He was ready to do any work in return for the treatment. We needed to get some wood to be cut for firewood. After three days of treatment with stones, I asked him to cut these big logs of wood. He used all his strength to cut the wood. To everyone's amazement, the snake stones remained firm on his shoulder. He went home after seven days. Now all my doubts vanished.

After this, people started coming from long distances. It was the krait that they were afraid of. The word had gone round that this little stone was able to save people, who were bitten by this treacherous snake. Since krait bite was common at night, they had to find some vehicle to bring the patients on time. If they could reach the health centre within 3-4 hours they could be saved. I cannot forget a particular family. Their village was about 30 kilometres away, an interior village without any transport facilities. At about midnight, the daughter of the family woke up and saw a snake on her mat. She screamed with fear. Her father saw that it was a krait. He was desperate. Fortunately, a

guest had come to the village on a two wheeler. The girl's father begged the visitor to bring them to Palliagaram health centre. It was an emergency and he obliged.

It was about 3 a.m. when they reached the health centre. Immediately, we applied several snake stones and we were sure that she would live. Meanwhile, I noticed that the father was muttering something to himself and looked very anxious. I asked him what the matter was. He said that he had other children who were sleeping on the same mat, and was wondering whom else the snake might have bitten, and what was happening to them. The visitor had already gone, and there was nothing the father could do. At about 6 a.m., he saw the inevitable happening. The family members had carried his son and walked up the main road to get the first bus. The bus had taken another hour to reach the health centre, by which time it was too late and the child was gasping for breath. Nothing could be done. In fact, as early as 4 a.m. the boy had developed symptoms like abdominal pain and blurred vision. The family had taken him to a nearby doctor, who had given him some injections, but nothing had helped. Without a vehicle, and with no proper medical care, the family had to watch their ten year old son losing the battle. The girl went home after a week. Fortunately, the snake had not bitten other members of the family.

Every sister in the community was taught to treat the patients with snake stones, because it was life saving and the method was simple. Thus, the sisters were able to save the lives of hundreds of young people, who, otherwise, would have died from snake poison. It is interesting to know that this stone is also highly effective in cases of other poisons, toxins and allergic diseases. The treatment with snake stones continues to benefit people over the years. The Health Centre Annual Report of 1997 recorded:

> In 1997 alone, we were able to save the lives of more than 300 young people bitten by poisonous snakes. It is really a marvel that these stones absorb poison from the

body without any discomfort to the patient and without any problem to the doctor. Moreover, the cost of the treatment is very reasonable and within the means of the poor.

Antivenom Treatment

Antivenom is the treatment recommended by WHO and so the allopathic system depends entirely on this mode of treatment. However, the very guidelines of WHO, regarding antivenom therapy, show that it is not always a satisfactory and simple treatment. The patient very often has to be treated for respiratory depression, renal and circulatory failure.

> Antivenom is the only effective antidote for snake venom. It is an essential element of treatment of systemic envenoming but may be insufficient on its own to save the patient's life. Antivenom may be expensive and in short supply.... It is recommended that antivenom be used only in patients in whom the benefits of treatment are considered to exceed the risks of antivenom reactions... No method of preventing antivenom reactions has been proved effective, including prophylactic epinephrine/ adrenaline.[4]

The guidelines further state,

> Antivenom treatment can be expected to neutralize free circulating venom, prevent progression of envenoming and allow recovery. However, these processes take time and the severely envenomed patient may require life support systems, such as, treatment of shock, assisted ventilation and renal dialysis, until the severely damaged organs and tissues have had time to recover.[5]

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[4] Ibid., p.77,78.

[5] Ibid., p.93.

No wonder doctors are diffident about treating patients who are victims of snakebite. More than 10% of patients treated with antivenom develop severe reactions, which are as life threatening as that of snake venom. Moreover, the effectiveness of the antivenom depends upon its composition. The widely used polyvalent antivenom may not be effective in all snakebites. The species specific antivenom is costly and may not be easily available.

Irula Tribals and Snake Venom

I was fortunate to come to know about the snake stones and to be able to save the lives of hundreds of young patients. These patients did not suffer from any complications of snake venom, that would have been there, if they had been treated with antivenom. People speak about many types of snake stones. I can only vouch for the snake stones that we use at our health centre.

They are available at : St. Thomas Mount,
Marikunnu P.O.,
Kozhikode 673 012
Kerala Ph: 0495-2370346.

The World Health Organization and other allopathic-minded experts consider herbal medicines and snake stones as useless practices.[6] Nevertheless, the part played by the *Irula* tribals of Tamil Nadu in obtaining the snake venom for production of anti-venom is widely acknowledged.

> India has a plentiful supply of anti-venom. For this, thanks is due, in large part, to the *Irula* tribe based in Tamil Nadu, who trap poisonous snakes and extract the venom needed for the manufacture of anti-venom. The real problem is

[6] Ibid., p.61

that many local hospitals do not know how to use it.[7]

The *Irula* tribals are reported to be in possession of excellent medico-botanical knowledge of herbal wealth, and related vegetation in their immediate vicinities. The main occupation of the *Irulas* is catching snakes and rats. Prior to the 1970s, these tribals used to sell the snake skin to the international market. Of course, the middlemen made most of the money and the tribals continued to be destitute. To add insult to injury, under The Indian Wildlife (Protection) Act 1972, the selling of snake skin was prohibited, and these tribals were on the point of starvation and death. Fortunately, the famous herpetologist and wildlife conservationist, Romulus Earl Whitaker, came to their rescue.

> In 1978, Romulus Whitaker and Mrs. Revathi Mukherji, a social activist, along with the Irulas sought the help of the Department of Industries and Commerce to begin a self-employment project, in order to promote the downtrodden and unemployed youth of their community. Thus was born the *"Irulas Snake Catchers Industrial Cooperative Society Limited"* and registered on 19 December 1978 with 26 members.[8]

After a struggle of a number of years, the *"Irulas Snake Catchers Industrial Cooperative Society Limited"* has proved its irreplaceable position, both in safeguarding the environment and as the sole suppliers of venom for the production of antivenom. It is important to know that the snakes caught by the *Irulas* are kept in captivity only for four weeks and then they are released in their natural habitat in a good healthy condition.

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[7] John Sudworth , op.cit.

[8] Dharamarajan, S. "Irula Tribe, Ecology and Business Innovation - A Case Study," *Conference on Global Competition & Competitiveness of Indian Corporate,* Indian Institute of Management, Kozhikode. http://hdl.handle.net/2259/515 May 19,2007

The *Irulas* are able to supply snake venom for the production of antivenom, only because they know the traditional herbal treatment for snake poisoning. In case they are bitten by a poisonous snake, they know how to treat themselves and they are sure of its effectiveness. No wonder that in case of snakebite, people, irrespective of caste or creed, seek out the *Irulas* for immediate treatment. Fortunately, Kancheepuram and Vellore Districts of Tamil Nadu have preserved the knowledge of these herbal medicines to some extent. There are research studies showing the effectiveness of these traditional systems of healing.[9]

> I am a little pencil in the hand of a writing God who is sending a love letter to the world.
>
> *MotherTeresa*

[9] T.Thirumalai, EK. Elumalai, S. Viviyan Therasa, B. Senthilkumar and E. David " Ethnobotanical Survey of Folklore Plants for the Treatment of Jaundice and Snakebites in Vellore Districts of Tamilnadu", *Ethnobotanical Leaflets 14: 529-36, 2010.*

3. No Superstitions Only Alternative Therapy

He said to the one who was paralyzed –"I say to you stand up and take your bed and go to your home." Immediately he stood up before them…(Luke 5:24-25)

It was May 1986 and the day temperature had been mercilessly high. The blazing sun was just setting in the western sky. A gentle breeze had begun blowing and I came out of the health centre to get some fresh air. I saw a distressed mother hugging her sick child and running on the road. She did not stop at our health centre. I was surprised. She kept running. I asked someone what was happening to that poor mother and the child. "The child is sick and they are going to Balamma. She knows to remove 'the bad air' and the child will be well. Balamma cures many people," was the answer. How superstitious and ignorant these people are, I thought.

One day Balamma herself came to the health centre for some treatment. I told her that I would like to see how she cured people of their illness. She was happy and took me to her village. Fortunately, a person who needed her service was waiting there. She took a bundle of neem leaves and stroked them all over the body of the affected person a number of times. After 5-10

minutes the person felt much better. I realized this was the same method used in Pranic and Reiki healing. The only difference was that Pranic and Reiki healers used their palms and not neem leaves. The medicinal properties of neem leaves are well known. They are very effective in viral infections. When I was a child, I had heard about the effectiveness of neem leaves in curing the dreaded and fatal disease, small pox. During a small pox epidemic, people made a paste of neem leaves and swallowed it every morning. This simple remedy ameliorated the course of the disease, and saved the lives of the affected people. My allopathic medical studies had caused amnesia to take over, all that was not of this system of medicine.

Balamma called the causative agent of the illness 'bad air or evil spirits' and the Pranic healers called it negative energy. Whereas Pranic and Reiki healers had set up big institutions and made money, here Balamma, and people like her treated the villagers for almost nothing. I told her that she could continue using this method if it helped people. Balamma also used herbal medicines to treat people. She knew her limits, and when the illness was beyond her skills, she told them to take the patients to the hospital. We, city bred medical practitioners, brand the customs and practices of villagers as superstitious. For centuries, traditional healers used their knowledge and skills to cure people. In the absence of doctors and hospitals in the villages, these traditional healers have played, and still continue to play, a great role in the health care system.

Another practice which, earlier, I had condemned as superstitious is the native herbal treatment of jaundice. People would come to the health centre with a circular burn mark on their upper arm. When I enquired what had caused the burn, they would tell me that they had suffered from jaundice and had been cured by this treatment. I used to laugh to myself and think that the healer

must be cheating them and making money. After all, about 80% of infective hepatitis A was self-limiting.

I continued to be sceptical until February 1994, when one of my friends, who had an open heart surgery, suffered from post transfusion hepatitis. The hospital admitted that the hepatitis B was caused by transfusion of blood. The hospital did what they could, but the patient was only becoming worse and was almost comatose. The doctors pleaded helplessness. At that juncture, someone suggested that the patient be taken for this particular herbal treatment by a native doctor. As it was a hopeless case, all agreed. Since I wanted to witness the process of the treatment, I accompanied the group.

Herbal Medicines for Jaundice

It was a small house. The person who was responsible for treating the patients (let us call him, 'native doctor'), looked at the patient and the only question he asked was why the patient was brought so late. All were sad and silent. He told us not to worry and that he was confident that the patient would recover. Since the patient was brought late and was in a serious condition, he had to use an increased dose of medicine, he said. The treatment consisted of just keeping a paste of herbs on the upper arm. The 'native doctor' also gave some medicine to be taken internally for two days. He explained that the medicine would burn the tissues a little and open up the pores of the skin, and the yellow fluid would ooze out. Can you imagine the cost of the treatment? It was just Rs.30! The patient started feeling better within 24 hours and, in a week, was back to normal health. There it was - the burn mark which I was sceptical about! After some years, when I went back to the medical college to update my knowledge and skills, I saw people comatose and dying of jaundice. How I wished that these patients could be treated by that 'little native doctor' and for so little money!

It is common knowledge that the allopathic system of medicine can offer very little to cure infective hepatitis (Jaundice). All that we advise is three weeks' rest and high carbohydrate diet, so that the liver can regenerate its damaged cells. In recent times, vaccines have been developed for hepatitis, caused by specific viruses. There are also antiviral drugs which are used to treat viral infections. However, by and large, in case of hepatitis, educated and illiterate, rich and poor alike, seek out someone who can advise them about herbal remedies. It is important, of course, to rule out obstructive jaundice. A study of herbal medicines in Vellore District, Tamil Nadu, showed that people use more than ten different types of herbs in the treatment of jaundice.[1] There are plenty of regional variations in the availability and use of these herbs and traditional medicine. One of the common medicinal plants used in south India is Phyllanthus amarus (*Keela nelli* in Tamil). Five or six plants are washed and ground into a paste, which is then mixed either in milk or buttermilk. The doctor, who cured my friend, told us that this therapy definitely worked but it had to be taken during the early stages of the disease.

The tribal people in our country also possess a rich knowledge of the herbal medicine.

> India has centuries old heritage of medicinal plants and herbal medicines for curing human illness. Medicinal plants form the only easily accessible health care alternative for most of our population in rural and tribal areas. The life, tradition and culture of tribals remained almost static since last several hundreds of years. The knowledge accrued by the tribals through generations shows the in-depth understanding of the forest resources... In the present study *Amomum aromaticum Roxb, Coccinia grandis (L.), Solanum indicum Linn,Terminalia bellirica (Gaertn.) Roxb.,*

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1 Thirumalai T., and others op.cit.

Tinospora cordifoliaL. plants were used for the treatment of jaundice. These plants were also used in other places of India in ethnomedicine.[2]

Recognizing Traditional Healers

Studies on medicinal plants were conducted also in Kancheepuram District, Tamil Nadu. According to this study, many people in the district, especially the poor, depend on traditional healers for their primary health needs. The documented medicinal plants were mostly used to cure skin diseases, poisonous bites, abdominal pain and nervous disorders.

> Traditional medical knowledge, of medicinal plants and their use by indigenous cultures, is useful, not only for conservation of cultural traditions and biodiversity, but also for community healthcare and drug development in the present and future.[3]

The study concluded that, even though western medicine, for simple and complicated diseases was accessible and available, many educated people in Kancheepuram District still continued to depend on medicinal plants.

The use of traditional medicines and home remedies is widespread all over the country, because these are part and parcel of our culture and social practices. It is also found that these traditional healers have good interaction with the patients, which is important for health care. Moreover, these herbal remedies are cheap and

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2 Mahendra Singh Choudhary and Ravi Upadhyay, "A Study on Indigenous Herbal Remedies Used to Cure Jaundice by Tribals from Central Narmada Valley of Madhya Pradesh" Life science leaflets (on-line)1,1-5, 2012.

3 Chellaiah Muthu, and others , "Medicinal plants used by Traditional Healers in Kancheepuram District of Tamil Nadu, India," *Journal of Ethnobiology and Ethnomedicine*, 2,43, 2006 http://www.ethnobiomed.com/content/2/1/43

so the poor, especially Dalits and tribals, prefer to use them for ordinary ailments. Unfortunately, the knowledge regarding these traditional medicines is fast disappearing. It is important to preserve this knowledge and to document these remedies, so that our younger generation may be familiar with these simple, readily available, medicinal plants and their uses. It is a matter of great satisfaction that, at present, the traditional systems of medicine, like Siddha, Ayurveda, Homeopathy and Unani, are officially recognized and patronized by our governments.

I told Balamma that I would like to have a gathering of the traditional healers from the neighbouring villages. She knew some of them. They contacted one another. They were surprised that they were being invited to come to the health centre, though they were familiar with the sisters and the health centre. The health centre was a small place and so they were not afraid to come.

There were thirty of them and they were happy that they were brought together for this meeting. "This is the first time in our life, we are recognized and appreciated for our services to the people", they said. As a rule, the knowledge of these remedies is passed on only within the particular family. It is not written down or printed in books. It has to be learnt by practice. The close supervision in the family perfects the practice. In the homely atmosphere of our centre, they shared their knowledge with one another. I requested them to share their knowledge with our village health workers to which they readily agreed.

Village Midwives

A friend from Germany told me that the second delivery of his wife was conducted in their home. She was on the floor and in the squatting position. The delivery was conducted smoothly and without any problem. There was a nurse to assist the process. It

was in 2004. Deliveries at home and the practice of traditional medicine are becoming popular in developed countries. I remembered our village midwives or Traditional Birth Attendants (TBAs), as they are called. For centuries, they had been conducting deliveries in the familiar atmosphere of homes, but there was no one to appreciate them.

These simple women, with their vast and valuable knowledge of pregnancy and delivery, are a great asset to the families in the rural areas. However, medical fraternity frowned upon these illiterate women and blamed them for the high maternal mortality rate in the country. It is true that they did not have modern facilities, and full scientific knowledge of anatomy and physiology of the human body. Instead of remedying this situation by organizing appropriate training for the village midwives, the government recommended that deliveries be conducted solely by doctors, nurses and midwives. Traditional birth attendants, trained or untrained are not included in this category[4]. In the government programmes the village midwives are called *Dais*.

> The training of *dais* began during the British era, aiming to reduce maternal death by instilling habits of 'hygiene.' In that class, racist, upper caste influenced context, *dais* were constructed as 'dangerous', undermining the legitimacy of the only caregivers who served the vast majority of women in India. The language, content and institutional arrangements were not only alienating but also disrespected their knowledge and skills.[5]

Later, the government of independent India continued the same mode of training, and so naturally the programme failed to

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[4] Park, op. cit., p.688.

[5] Mira Sadgopal, "Can Maternity Services Open Up to the Indigenous Traditions of Midwifery?",*Economic and Political Weekly*, Vol.XLIV,No.16, (2009):p. 53.

produce the intended result. The village midwives continued to bear the brunt for the high maternal mortality rate. The trainers failed to take into consideration the age- old effective skills of the village midwives. In fact, their practices are a blend of traditional knowledge, skills, experienced insights and culturally significant rituals.

Fortunately for the village midwives, many of their childbirth practices have recently found scientific validity. Many NGOs in India and abroad are promoting these time tested practices. Among them are :

> a) Squatting and movement during labour: This traditional position in labour aligns the womb's vertical axis with the gravitational force and not so the lithotomy position(lying flat). b) Continuous care-giving support during labour: This meets the emotional, physical and social needs of labouring women and enhances the progress of labour. Many other positive practices of these traditional midwives are now acknowledged as useful by some of the medical practitioners. The delayed cord cutting and its beneficial effects for the new born is yet another such practice.[6]

Mira Sadgopal is a medical doctor and a health activist. She deplores the antagonistic attitude of the allopathic doctors towards the village midwives .She wrote in the same article that it was astonishing that the doctors could discredit and discard such methods as being the practices of 'illiterate and uncouth women', when in fact, these were the techniques evolved by women's experiences, by being traditional birth attendants for centuries. According to her, some of these women are adept in reversing breech and transverse positions of the foetuses and thus delivering them vaginally. They also have different traditional methods for expelling the retained placenta. We are

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6 Ibid., p.55.

not contending that everything that these village midwives do is perfect; we are only saying, that with suitable training and with a little support from the medical circles, these women can be a great asset to the maternal and child care programmes.

In the year 2000, the world leaders at the head quarters of The United Nations in New York adopted The United Nations Millennium Declaration. 189 countries, including India endorsed the Declaration and committed to free people from extreme poverty and hunger, achieve universal primary education, promote gender equality and empowerment of women, reduce child mortality, improve maternal health, combat HIV/AIDS and other diseases ,ensure environmental sustainability and develop a global partnership for development. The year 2015 was set as the deadline for achieving these eight Millennium Development Goals with its country specific targets.

Accordingly, India is supposed to achieve the reduction of Maternal Mortality Rate (MMR) from 327 in 1999-2001 to 109 by 2015. MMR measures the number of women aged 15-49 years, dying due to maternal causes per 1,00,000 live births. No doubt the country has made progress, and the concerted effort of The Central and State Health and Family Welfare Ministries has resulted in reduction of the maternal mortality rate from 327 to 212 in 2009. All the same, with 60% of deliveries in India still being conducted in homes, will the country achieve the goal of 109?

They were Eager to Learn

Many a time it is not possible for the poor in rural areas to reach a hospital on time for delivery. In the absence of transport and other communication facilities, what could people do but depend on traditional midwives? Again Balamma came to my rescue. She herself was a traditional midwife. I told her to contact the

midwives in other villages. I designed a training programme for these women. Every village had a midwife, who conducted the deliveries and took care of the pregnant women. They knew that they were being blamed for the high maternal mortality rate.

Fifty of them were trained in two batches. They were eager to learn. It was a five day programme. I taught them basic anatomy and physiology; importance of antenatal and post natal care and immunization; importance of hand washing and sterilization of instruments, and safe methods of conducting the delivery. They had opportunity to clear their doubts and questions. What they appreciated most was, that I respected their traditional knowledge and skills, and that I wanted them to continue to be of service to the people. They were made to feel, and rightly so that they were an indispensible link in the maternal and child care services.

I involved PHC nurses in the training programme, and they were reminded of their responsibility of providing antenatal services for pregnant mothers. They were motivated to cooperate with village midwives. I told them that if they had any problem I was there to help them. At night, without any vehicle or ambulance at their disposal, attending on pregnant mothers was an ordeal for both the PHC nurses, as well as for the village midwives. Now they were very happy that they could bring the patients, with complications of delivery, to our health centre. If any complications were detected during antenatal check-ups, they would be referred to the hospitals. Safe home deliveries became the norm in the villages. This freed my hands to attend to other emergency cases.

Thus I became a believer in alternative system of medicine, as well as in the traditional wisdom of people. I myself did a course on acupuncture and treated certain chronic diseases with this system. Another sister was trained in homeopathy. This is not to undervalue the merits of allopathic medicines. Every system

has its merits as well as its limitations. Allopathic system with its diagnostic technology, and surgical advancement is invaluable in many of the medical and surgical conditions. However, there is also place for other systems of medicine, even though we may not understand how these herbs and medicines work. In spite of the primitive conditions of their living, the poor survive only because of their inborn instincts and traditional knowledge which is passed on from generation to generation.

Traditional medicine is the
sum total of knowledge,
skills and practices based on the theories,
beliefs and experiences, indigenous
to different cultures
that are used to maintain health, as well as to
prevent, diagnose, improve or treat physical
and mental illnesses.

World Health Organization, Traditional medicine, Fact sheet No.134, 2008

4. Caste System A Chronic Disease and a National Shame

What does the Lord require of you but to do justice, and to love kindness and to walk humbly with your God? (Micah 6: 8)

The caste system is a cultural pathology that affects the very fabric of the Indian social system. The caste system in India has been affecting the life of Indians from time immemorial. You may not agree with me if I quote a very valid statement, that in India, "The Cow is more sacred and valued than humans". I am sure you have not forgotten the incident, that shocked the nation on 16 October 2002, when five Dalit youths at Jajhar in Haryana, were chased and brutally lynched for carrying a dead cow. Yet, the fact was that they had not killed the cow. I was very shocked and sad to read this news, that the religious fanatics killed these innocent human beings in the name of the 'holy cow.' A fifth of the Indian population has been suffering this humiliation for more than three millennia.

The religious legitimization of the caste factor is symbolically illustrated in the *Primal Purusha*-Rig Veda

> 10.90.v12:' The Brahmin was his mouth, and his arms were made the Rajanya; his thighs became the Vaisya, and from his feet was the Shudra born'. This sacralization of the fourfold *varnas* is intrinsic to the dominant Hindu religion.[1]

There is a fifth group which does not belong to any of these four caste groups. They are considered as polluting, untouchables or outcastes. The concept of 'purity and pollution' are at the root of the caste system. The untouchables are officially known as scheduled castes, but they prefer to be known as Dalits, a term much used by Dr. Baba Saheb Ambedkar. The meaning of the term 'Dalit' is 'broken, crushed and oppressed'.

The caste system of India illustrates the most rigid and detailed form of stratification of the society.

> Caste has always acted as a leverage of power in the Indian society. It confers power on some and denies power to others. This power may be social, economic and political... Castes at the bottom of the social hierarchy neither had the means nor the ideological base needed to challenge the authority of those in power.[2]

In a class system, upward social mobility is possible, but in the caste system this is not possible. According to Hindu religious tradition, a person was born into a particular caste and it was not possible for him/her to get out of it.

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[1] Margaret Shanthi, John Soosaimanickam, and Bosco ed., *Awakening to our Human Dignity and Rights.* Hyderabad: The National Forum of Religious for Justice & Peace. 2003, pp. 17-18.

[2] Indira R., "Caste Politics in India", in *India a People Betrayed*, ed.,Dasan A.S.and Bhamy.V.Shenoy , Mysore : Goodwill Fellowship Academy, 1993. P.35

These are not Fairy Tales

It is true that, in 1950, the Indian Republic legally abolished untouchability. But the ground realities are very different. We are no strangers to the headlines in the newspapers, such as: "Dalit sugarcane worker burnt to death in Chincholi, Maharashtra", "Dalit woman paraded naked by five persons of upper caste at Mulgaon village, Maharashtra", "Ever after fire, Bolangir villagers live in fear of upper caste neighbours". All these three incidents occurred in January 2012. Thus, in this twenty first century, the atrocities against Dalits continue unabated, not in the villages, but in cities; not among the illiterates, but among the educated. The *Deccan Herald* of 14.3.2012 reported that in Mysore city a 27-year old woman, Shruthi, was killed by her brother for marrying a Dalit, who was an assistant director of physical education in Tumkur University. Shruthi was also an assistant professor in a government college. The news report further stated that, three months prior to this incident in Mandya, a man hanged his daughter for falling in love with a Dalit boy. What are we to think about the following incident? A Dalit boy was thirsty and drank water from the water pot of an upper caste person, which was found on his premises. The Dalit boy's hand was chopped off immediately with a sickle. This happened on 15 February 2012.

What is most deplorable about these crimes is that the culprits, who perpetrate these cruelties, are let off without being convicted. Bathani tola is a village in Bhojpur District of Central Bihar. In 1996, a number of Dalit men, women and children were hacked and massacred by upper caste people . There were teen age girls among them, as also babies less than ten months old. *Ranvir Sena* (a private militia of the landlords), was responsible for this carnage. The accused were convicted by the sessions court in Ara District in May 2010. However, in 2012, the Patna High Court allowed these heartless murderers to walk out of jail. Naturally,

the rich and powerful landlords are triumphant at their victory. Is there any wonder that any Dalit, who dares to raise his /her voice against the injustices their people suffer, is hunted down and, not only the individual, but the entire village is burnt, and people are brutally killed? In spite of the daylight, large-scale carnage of Bathani tola , the culprits were acquitted because of "defective evidence". The editorial of *The Hindu* on 25 April 2012 made the intrepid statement: "It is important that we do not allow our attention to be diverted and justice to be subverted in this case, merely because the victims were poor and landless Dalits, living in a remote village in the Bihar hinterland."

I have enumerated these three or four relatively recent cases of attacks and murder, which were reported in the newspapers, to show that the atrocities and violence against Dalits are a continuing phenomenon in India. Unfortunately, most of these atrocities are not reported, because Dalits are not even allowed to enter the police stations. Shura Darapuri wrote on the Op-Ed Page of the *Hindu* on 25 March 2012, that:

> 27.6% of Dalits are still prevented from entering police stations and 25.7% from entering ration shops. 30% of public health workers refuse to visit Dalit homes and 23.5% of Dalits still do not get letters delivered at their homes.

Shura Darapuri continued with a long list of facts, where Dalits are deprived of their rights to the social and economic life of the country. The reported cases are only the tips of the iceberg of what is happening to Dalits in our country. Many more of these atrocities go unreported.

> There is no change in the minds of the Caste Hindus when it comes to the dignity of Dalits. The atrocity data in the Sixth Report of the Commission of Scheduled Caste and

> Scheduled Tribes in 1999-2000 and 2000-2001 proves this point. According to the report, 23,742 atrocity cases against Dalits took place in the year 2000 alone. Out of 23,742 cases 1,034 were rape cases of Dalit women and 3,241 murders: an average of three cases of rape and nine murders per day.[3]

Is there no escape from this caste conundrum? It seems to be no, for now at least. When a Dalit educates himself well, he does not escape caste, but only becomes an educated Dalit. When a Dalit changes his religion, and, say, embraces Christianity, he becomes a Dalit Christian. Surprisingly, when a Dalit becomes even the president of India, he is a Dalit president. The caste tag goes with the person to his/her grave. That is India, surging ahead in becoming a super power - of course, without shedding the shameful caste tag. The conclusions of the research carried out by Gaikwad prove this fact. He interviewed about 200 college students and employed Dalits in Aurangabad. "Whereas, all the respondents were eager to do away with caste stigmatizing identity, they felt deeply that they continued to be discriminated against." 80.5% of Dalits stated that contrary to their expectations the caste Hindus did not invite Dalits to their homes, dine with them, or enter into meaningful and rewarding social relationships. [4]

Silence is Consent

I was happy that more than 90% of the patients who came to our health centre were Dalits. The rest were caste people, who valued our medical services for their effectiveness and affordability. The

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[3] Sunny Jacob, "Dalit's Quest for Dignity", *Indian Currents*, 22 December (2002):p.36.

[4] Neera Chandhoke, "Why People should not be Poor", *Economic and Political Weekly*,Vol.XLVII,No14,(,2012): p.47.

rich wanted our services, but they were neither concerned nor sympathetic towards the poor. When people came to the health centre, I gave them the best medical care I could and they were happy. I could understand the situation of the poor to some extent, but I could not understand why certain sections of people had all the privileges, whereas other groups were treated with contempt. With only a few minutes available for each patient, I could not enter into all their problems. On days when there were fewer patients, the people would speak a little more of their life situation, and their talk gave me some insight into the ramifications of the caste system.

It was strange for me to hear that Dalits were not allowed to walk on the streets of caste people; neither could they draw water from their wells. In fact, the term 'village' applied only to the area where upper caste people lived. Dalit colonies were located at a distance of 1-2 kms away from the village. What was more shocking was that the government had separate schools for children of the caste people and for those of the Dalits. The government *balwadis* (day care centres) were located only in the upper caste area and the children of Dalit families were not allowed there.

Was it not a blatant unjust system, where the little ones of the poor families were deprived of the nutritious food and care of the *balwadis*, whereas the children of the rich families enjoyed these benefits? While the parents worked in the fields as daily labourers, the pre-school age children of the Dalit families had nowhere to go. The older siblings, almost always the girls, looked after their younger siblings. They had hardly any food, except perhaps, some rice that might be left over from the previous day's cooking. As a result, malnutrition was rampant among these children. Mothers brought these malnourished children to the health centre. They thought that medicines would make

them healthy. What they needed was sufficient food to eat and safe water to drink.

It was good that these unjust systems disturbed me. But what could I, as an individual, do against this all-pervading unjust system of the society? Silence is consent, it is said. Therefore, I decided to break my silence, and talk to the people about the caste problem, that was at the root of most socio-economic and political problems, and was also the cause of many physical and mental illnesses.

By 8 a.m., already sixty to seventy patients used to be at the health centre to be seen in the OPD. We usually started the clinic with a small prayer and a pep talk of 2-3 minutes. Besides the topics of health and nutrition, I included some social themes such as equality, dignity of human beings and so on. The content of these talks went more or less like this:

> As a doctor, I have treated thousands of patients and had their blood tested. It was found that the blood from all people had the same characteristics, except in the case of particular diseases. Whatever might be our religion, caste, or gender, all human beings are created by God and all of us are brothers and sisters. A person, however poor or of whatever caste, needs to be respected. The differences and divisions are created by human beings and not by God.

This message was repeated, day after day and month after month, in different words and forms. This had the desired effect. The rich and the high caste people knew that they could not expect any preferential treatment at our health centre. Some of the landlords, did expect that I see them before I started with the 'common crowd.' I told them politely that I would see the patients only according to the token system. The poor came as early as

4 a.m., so that they would be able to go back and earn a day's wages. If I had any preference, it would be for these people.

Stating the Obvious

According to the UNICEF report of 2008, child malnutrition in rural India is about 50%. The overall average of the country is not much better. *"42% of Indian children are malnourished. Prime Minister Manmohan calls the new report's findings a national shame",* reported *The Hindu* and other newspapers on 11 January 2012. TV channels also had been flashing the news from the previous day. This news report called 'HUNGAMA' (Hunger and Malnutrition) states that "the prevalence of malnutrition is significantly higher among children from low income families. It found that children from Muslim or SC/ST households had worse nutrition indicators." I did not need to read the statistical reports to know what was happening to children in the Dalit colonies. I had been seeing them day after day in the health centre. I was just wondering, whether they needed to spend so much money on the survey to state the obvious facts, which the UNICEF and others had been publishing year after year.

"Malnutrition makes the children more susceptible to infection, recovery from disease is slower and mortality higher. Undernourished children do not grow to their full potential of physical and mental abilities."[5] Malnutrition in early childhood has serious, long term consequences, because it affects brain development and impedes motor, sensory, cognitive, social and emotional development.

> India wants to reach the moon but the question is whether it can reach its own starving children...Gandhiji said that,

[5] Park, op.cit., p.406 .

when in doubt, think of the poorest and the weakest; as to how your decision is going to affect them. Are they thinking of the marginalised and the most vulnerable; the hungry and starving poor children?" (Prahalad Singh, The Hindu, 25.7.2010)

A Simple Intervention

I knew that a crèche in Dalit colonies would take care of the nutritional and developmental problems of these pre-school children. However, people were not familiar with the idea of caring for children in a crèche. I explained to them what a crèche was and its functions. People in the Dalit colony of Palliagaram held meetings to discuss the idea of a crèche. They wondered how other people would be interested in taking care of their children. Women were concerned about their children, and so they told me that they would like to have a crèche started in their village. Being a Dalit colony, they did not have any community hall or any other common place where the crèche could be located. I told them to find a small piece of land for this purpose. Through their persistence and perseverance, the women managed to get a small piece of land right in the centre of their colony. The crèche had to be a common venture of everyone in the colony. So, every family contributed either labour or cash towards the construction of a small one room building. The sisters also contributed a part of the cash that was required for the construction.

The crèche started functioning, at first with a few children. We helped them with food materials and the salary of two helpers, who would cook nutritious meals for the children. The parents came around, and watched how the children were being taken care of by strangers. What they saw amazed them. The children continued to increase in number. Our sisters supervised the crèche, and saw to the psycho-social development of the children.

With nutritious noon meals and snacks in between, the weight of the children improved and their eyes sparkled. They sang and danced and learnt rhymes and numbers. Since the crèche was in the colony itself, mothers could leave them there before they went to work. This enabled the older girls to go to school. Very soon the children improved in health and nutritional status.

A Visit from the City

Some professors from The Madras School of Social Work came to see our work. They were interested to have a first-hand knowledge of the situation of the villages. I took them to the Dalit colony of Palliagaram. The health centre was situated on the main road, and the village was at some distance from the road. We crossed the road and walked towards the village. It was early morning. It took about ten minutes to reach the houses of the upper caste people. Rows of houses with tiled roofs and others with terraces, came into view. Then there were the temple, the school and the *balwadi,* all exclusively for the use of upper castes. We walked on and entered the narrow pathways through the green paddy fields. 'These paddy fields and pump houses belong to the upper caste people and the Dalits work in these fields as daily laborers.', I explained to the professors. By now, we had walked about two kilometres and finally entered the Dalit colony.

The contrast between the houses of the upper caste people, and the Dalits was quite obvious and did not need any explanation. The roofs of these tiny thatched one room huts were so low that the visitors found it difficult to enter the houses. Some of them doubled up and managed to enter one or two houses. The stark poverty of the people and the lack of amenities in the colony made these city people sad. The huts lined either side of the narrow winding muddy paths. There were about four hundred families living in these rows of huts.

It was about 8.30 a.m. As we walked through the narrow lanes of the colony, we saw that mothers and grandmothers were busily occupied. We were pleasantly surprised to see that they were bathing their little ones, combing their hair and powdering them. The women and children waved out happily. The women explained that the children refused to go to the crèche, unless they were bathed and cleaned. Some of these tiny tots were already walking towards the crèche.

It was a matter of satisfaction, that the little ones were teaching the adults about the necessity of cleanliness and hygiene. No more stench or leaky noses or unkempt hair for them. Initially, the sisters bathed them and cleaned them. The children felt better and became healthy. Then the sisters told the children to ask their mothers to clean them. Small as they were, they were able to convince their mothers to do the needful, and mothers learnt the importance of hygienic health practices. Any number of theoretical classes would not have effected this change.

A Transforming Effect

The news of the crèche and its positive effects spread to the Dalit colonies of other villages. People demanded that the government *balwadi* should function in Dalit colonies as well. The protests and perseverance of the people were rewarded. The government conceded to their demand and started opening these Child Care Centres for the Dalit families. What happened in Palliagaram was even more surprising. About 40 children attended the crèche in Palliagaram colony .It was functioning very well, whereas the *balwadi* in the upper caste area had hardly any children, and the staff there were in danger of losing their jobs. They therefore, came to the crèche in the colony to learn the method of conducting the crèche. They also said that they would admit all the children from the Dalit colony.

Whatever the motive for admitting the Dalit children into the *balwadi*, it was a good move. We made sure that all the pre-school children from the colony were admitted and cared for in the government *balwadi*. We closed the crèche and the building was handed over to the women to conduct their meetings.

Thus, the crèche in Palliagaram colony improved the nutritional status and health of the children of this village, and of the neighbouring villages. It was also instrumental in bridging the caste gap, at least in a small way. Nevertheless, I am aware that the caste problem is embedded deep in the Indian psyche. It is a volcano, which can erupt at any moment, as the following incident will prove. It was a Sunday evening, and I thought I would relax for a little while with my sisters in the convent. In no time, we saw a crowd of people shouting and rushing to the parish house. For the first three years, the office of the Social Action Movement (SAM) had been functioning in the parish house. The people had to pass by the convent gate to go there. I realized that all of them were the upper caste people from Palliagaram village. They carried sticks and rods and were in a terribly agitated and angry mood, ready to beat up anyone who came their way.

I stopped them at our gate. They were flabbergasted that I, a woman, dared to halt them. I asked them what the matter was! After all, they would need me and the health centre in any medical emergency situation.

> How can the Dalits, (actually they used the term 'pariahs' and other insulting words) go ahead of us, in front of us, and have their houses built closer to the main road? SAM is planning to build houses for these people close to our houses. Now Dalits will be closer to the main road and not we. We cannot allow this,

they shouted. I tried to placate them. I told them, that they were educated and intelligent people, and with a lot of sense in their heads. I made them feel very important, saying that they were the ones who should have helped us to be of service to these people. I kept speaking to them, until they calmed down and could see the light of reason. Finally, they turned and went back to the village. Since they would have to face me in emergency situations, they let go of the matter, at least for the present. Finally, the houses were built closer to the houses of the upper caste people. I was happy that I could use my professional authority, both as a religious woman and as a medical doctor, to avert a caste clash and violence.

A Ray of Hope

Even as the violence against Dalits is increasing, there is a simultaneous awakening of their rights among them. This community is slowly being awakened. They are no longer submissive, as they used to be. The sporadic efforts of the Dalit activists of earlier times, have now become organized and widespread. It has become a National Movement. In 1998, the Dalit leaders initiated the National Campaign on Dalit Human Rights. The objective of this campaign was to give visibility to the Dalits, and to raise awareness among them, as well as among the government officials and NGOs, that the violation of Dalit rights is the violation of human rights. They were able to bring together Dalit activists from 12 states and union territories, thus forging unity among the Dalit leaders and movements.

Moreover, the Dalit intellectuals are publishing literature and these books offer social critiques on Brahminism, the struggles and sufferings of Dalits and so on. Happily for the Dalits, many of these books and pamphlets are written in easily readable style and are available at affordable cost. They are finding their way to

Dalit rallies and protest meetings. Badri Narayan, writing in OP-ED page of *The Hindu, on* 3.5.2012, said that the Dalit literature has been able to awaken their quest for dignity and, consequently, many meetings are being held in U.P. villages, to protest against the recent escalation of violence perpetrated on the Dalits and other oppressed groups.

Even so, caste consciousness is a chronic disease, for which there is no easy remedy. The origin and cause of the caste system is so complex and so interwoven with every aspect of the socio-political and religious life of Indian society, that the rooting out of this cancerous disease seems to be a distant dream. Still, lighting a tiny candle is better than cursing the darkness.

> Untouchability is another appellation for slavery. No race can be raised by destroying its self-respect. So if you really want to uplift the untouchables, you must treat them in the social order as free citizens, free to carve out their destiny.
>
> *Dr. B.R. Ambedkar*

5. Poverty, a Cruel Malady

Is not this the fast I choose: to loose the bonds of injustice, to undo the thongs of the yoke, to let the oppressed go free and to break every yoke? (Isaiah 58: 6)

Poverty is ugly. Poverty is cruel. Poverty is unacceptable. But why do you worry about poverty and its ugliness? Anything that is ugly can be garbed in a beauteous exterior. So, where is the problem? The government officials of Delhi, planted fast growing shrubs and bamboos well ahead of the Commonwealth Games of October 2010.[1] This would cover up the ugly sight of slums, beggars and the Delhi's poor labourers from the view of visiting foreign dignitaries and tourists. Moreover, poverty can be less jarring to the ears if it is described in medical jargon, such as stunting, underweight and malnutrition. These medical terms are more acceptable to the politicians and bureaucrats. Medical records would show, perhaps, the number of children who died of malnutrition but never of poverty and hunger. Yet, can we deny the existence of the poor in our country?

Poverty is a complex issue. Perhaps it can be defined as a condition, in which a person earns so little that he/she cannot provide two square meals per day for his/her family and cannot

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1 George Plathottam, "A Bamboo Cover on Poverty", *Indian currents* Vol. XXI, No.52, (2009):p.30.

provide adequate shelter and clothing for them. Public health experts have always recognized the effects of poverty on health. However, doctors usually shy away from attributing poverty as a causative agent of diseases.

> Poverty wields its destructive influence at every stage of human life from the moment of conception to the grave. Poverty is the main cause why babies are not vaccinated, clean water and sanitation are not provided, and curative drugs and other treatments are unavailable.[2]

Poverty is the main reason why people are malnourished, and why people have no safe and hygienic dwellings. Is there anything more mortifying for a country, than the children of the poor, who are forced to eat mud and silica to assuage their hunger? This happened in Allahabad District, in the village of Ganne and was reported in *The Hindustan Times* on 4 April 2010. As Amartya Sen terms it, 'persistent mass hunger' and acute malnutrition among children are widely prevalent in the country.

According to the government statistics, 91% of urban population and 94% of rural population are supplied safe drinking water. However, recently available statistics, which were compiled through the collaboration of the government and an international NGO 'WaterAid', states that over 37.7 million people in India are affected by water-borne diseases, due to contaminated drinking water supply, and an estimated 1.5 million children die of diarrohea each year. You can very well imagine the type of people, who suffer the consequences of this water scarcity and contaminated water supply. The vast majority of Dalits, tribals, daily labourers, slum dwellers and the homeless belong to this category.

UNICEF statistics reveal, that over one-third of the world's population, that lives without access to sanitation, lives in India.

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[2] Park, op.cit., p.516.

Even according to government statistics, only 31% of the urban population and 21% of rural population have accessibility to improved sanitation. It means that about 50% of Indians do not have any sanitation facilities. Statistics indicate, that the intestinal group of diseases claims about 5 million lives every year, while another 50 million people suffer from these infections.[3]

When it comes to housing, it is no better. More than 300 million of India's population live in slums and squatter settlements, in inhuman conditions that deny them dignity, shelter, security, and the right to basic civic amenities of social services; they live in an environment which harbours crime, ill-health and disease. These conditions of sickness and disease, unemployment and crime draw them deeper into vulnerability and poverty.[4] Overcrowded, ill ventilated houses are responsible for respiratory diseases including tuberculosis, bronchitis and whooping cough. Many times, the huts of the poor, whether in slums or in the rural areas are flooded, and the floors are damp and dirty, giving rise to skin infections and fevers. Rats and snakes find their way to these dwellings. Houseflies and mosquitoes, fleas and bugs are common. In such conditions, both morbidity and mortality rates are high. There are of course, large segments of the population who do not have even the luxury of slums. They live on pavements, railway stations or market places. They have nothing to call as their own.

Is Poverty a Number Game ?

Even as 'Food Bazars', MacDonald's and KFCs spring up in every city and even in small towns, 50% of Indians, that is a staggering number of more than 500 million are chronically

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3 Park, op.cit. p. 563.

4 "Report of the Committee on Slum Statistics/Census", New Delhi: Govt. of India, Ministry of Housing and Urban Poverty Alleviation ,National Building Organisation 2010.p.1. http://mhupa.gov.in/W_new/slum_Report_NBO.pdf

hungry. Agriculture has become agro-business. In the name of development, the marginal farmers have lost the little land they used to cultivate. With cancellation and reduction of subsidies, the small farmers are desperate. Their inability to pay back the loans and with their dignity at stake, they can think of no other option, except to commit suicide. With the fast growing food industry, where is the food left for the poor? As per the Report of the Subcommittee on Food and Nutrition, and as reported in *The Hindu* on 22 February 2012, in Karnataka alone, 33,02,370 children suffer from varying degrees of malnutrition. In fact the words, 'poor and poverty' have become inconvenient, uncomfortable terms. The parliamentarians debate endlessly about the definition of 'below poverty line' (BPL), depending on the statistics they want to project. In 1978, BPL was fixed, based on the cost of food grains that gave 2,400 calories for those living in rural areas, and 2,100 calories in urban areas. However, in 1990s, there was pressure on the government to reduce the number of people living in poverty. The government found an easy way to reduce the number of poor people by just lowering the calorie needs of the poor! Moreover, the number of people, who could be under 'below poverty line' was prefixed.

The Starvation Line

This number game continues, and will continue as long as the government is concerned, only with impressing the international community, and not really committed to eradicating poverty and hunger from the country. In The Millennium Declaration of September 2000, 189 member states, including India made a passionate commitment to address the crippling poverty and multiplying misery, that grip many areas of the world. They set 2015 as the time line, by which they would achieve the goals laid down in The Millennium Development Goals, the first of which is to 'eradicate poverty'.[5]

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[5] Park, op.cit.,p.28.

As time is running out, and we shall be there in 2015 very soon, the government is desperate to record lower poverty statistics. "Now, The Planning commission lowers the poverty line.", announced the newspapers on 20 March 2012.

> The Planning Commission on Monday released the latest poverty estimates for the country showing a decline in the incidence of poverty by 7.3% over the past five years and stating that anyone with a daily consumption expenditure of Rs.28.35 and Rs.22.42 in urban and rural areas respectively is above the poverty line. (*The Hindu* 20.3.2012).

Thus, the government absolved itself from the responsibility, of providing adequate food materials for millions of its starving people.

Can anyone with a conscience stomach this hypocrisy of the politicians and bureaucrats? "The people who are starving and hungry, and whose hard physical labour is beyond any comparison, are denied even what is minimum."[6] A lower middle class person buys one kilo of low quality rice at the cost of twenty two rupees and, for the poor it suffices to have a daily income of Rs.28.35 in urban areas and Rs.22.42 in rural areas! Is this not a statistical jugglery? 'Below poverty Line' is rightly called starvation line because it is calculated on the bare minimum of calories, that is needed to subsist on. People living 'below poverty line', suffer from starvation and so, they are chronically hungry and malnourished.

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[6] Sister Agnesita, "The Indian Urban Health System: A Paradox and a Polarisation", in *Urban Health System*, ed., P.K.Umashankar and Girish K.Misra, New Delhi: Reliance Publishing House &The Indian Institute of Public Administration, 1993. p.190.

Kannan and His Daughter

Let me come back to my health centre at Palliagaram village. Kannan was restless and desperate. He was waiting for his token number to be called. He had brought his three year old daughter, a severely malnourished child, with a protruding abdomen and swollen limbs. The child was listless. I examined the child. Providentially, I had a little more time that day to talk to Kannan. I told him that the problem was due to lack of sufficient food, and gave him a list of nutritious food materials, that he could purchase and feed the child with. I had not yet started preparing the 'flour mix', and so I had to explain to him the details of food materials, and the frequency of feeding the child. I told him of the consequences if he did not follow my advice. He listened to my speech patiently. When I stopped my long medical advice, he answered me in a whispering tone,

> Doctor, I have three other children and my wife and parents to look after. Our fire place burns only once a day. If I look after the sick child the way you advise me, then even that 'once a day' meal might not be there for others.

I could see on his face that it was a hard option for him to make.

I remember that, at the medical college, I had the difficulty learning the definition of 'poverty line' as part of Preventive and Social Medicine. Here, in the health centre, I was seeing, day after day, the effects of acute poverty. During my first few months in Palliagaram, I used to be desperate and angry when people brought their patients, when almost nothing could be done. I was at my wit's end, when the patient was a child. I presumed that they did not care for their children, and that they were ignorant and superstitious. It looked as though I was more desperate for the life of the patient than they were.

Later on, when I had the opportunity to visit the Dalit colonies, I saw the small huts which they called their home. You had to

bend double if you wanted to enter these huts. They told me that they cooked food only in the evening. If anything was left of the evening meal, they would eat it in the morning and go for the day's work. The quality and quantity of what they cooked, depended on the daily wages they received. Now I did not need books and definitions to know what was meant by 'Below Poverty Line' (BPL). The poor who came for treatment were the living definitions of BPL.

Reaching out to people

When people live a hand to mouth existence, health cannot be a priority for them. Kannan had already explained to me, that the sickness and treatment of one person in the family, meant hunger and deprivation for other members. Compounded with this problem of poverty, was also the problem of lack of transport and communication facilities. People had to walk a distance of 5-6 kilometres to reach a main road, and they waited for hours to get into an occasional bus that might pass that way. For us city folks, this may sound as a fairy tale, but people living and working in remote villages know, that this is the harsh reality of rural India. In case of sickness and death, there is nothing the poor can do, but accept these misfortunes as their fate.

As a remedy to this situation, the sisters had started conducting mobile clinics, even before I came to Palliagaram. There were weekly visits to four villages. In these evening clinics, we were available for people for their medical needs. People from the surrounding villages could come there for treatment. More than one hundred patients were regularly seen, and treated in each of these centres. People were happy that our services were regular and efficient. People from the interior villages made use of our medical services.

In the morning we were busy at the health centre with patients until 2- 3 p.m. At 4 p.m. we would start for the villages. As you may

imagine, we were dead tired by 7 p.m. and would start closing up the mobile clinic. Week after week, I noticed that some people came only after 7 p.m. I started losing my patience, and would tell them that I had been working the whole day, and was tired. I would also have to attend to the emergency cases at night and so, they should come earlier; otherwise I would not be able to help them. That was my stern response to them.

A Reflective Process

I used to come back dejected from these mobile clinics. It was a conflicting situation. My desire to reach out to people was the motivating factor for going to the villages. However, I was physically tired and had no more energy to carry on. I could not help the people who actually needed my service. Meanwhile, some one enlightened me, that the people who came late were Dalits. I also became aware that we, in our ignorance of the caste system, were conducting the clinics in the high caste area. Naturally, the Dalits were afraid to come there. Even if they dared to come, they could do so only after completing all the work demanded by the landlords. By the time they walked from the colonies to the place, where the clinic was being conducted, it was usually late. Here was the irony of the situation. We thought that we were conducting the mobile clinics, so that medical care became both accessible and affordable to the poor. In reality, what was happening, was that we were unwittingly catering to the relatively rich, and neglecting the poor. The poor were invisible and far removed from the main villages. This disturbed me not a little. We were working day and night, stretching our meagre resources to the maximum for the welfare of the people, yet, who were benefiting from our services? For whom was I spending my energy? These and many such questions haunted me.

I was determined to act. The next time when I went to

Thiruvanthavar village, I told the leaders there, that I would be shifting the clinic to the Dalit colony. They were surprised at this move. This was my decision. What could they do? The fact of being a doctor and a woman helped me. This happened as early as 1979. I told them that I would be available in the colony, and that they were free to come there for any medical help they needed. In emergency cases, a few of them did come to the colony and I was happy for that.

I started going to the Dalit colonies. There were no queues and crowds. People would come for treatment only after they finished their work. This gave me time to visit the families. I sat with them in their little huts. They would talk to me about their problems and troubles. Some women, and the old and the sick would be in the houses. I could treat the sick in a more leisurely way and give them the time and attention they needed. I slowly started to understand, what it meant to be on the lowest rung of the society. I was happy for the decision that I made to shift the clinic to the Dalit colonies. I was relaxed and was available to the people when they came, after a day's hard work. They were happy that they did not need, either to walk long distances to get the medical help or be frightened to go to the upper caste area.

The Right not to be Poor

> The link between poverty and human rights has been made with increased frequency in the last few years. This attention to both the causal and normative aspects of this link coincides with the deepening of human rights understanding in international circles and the more consistent approach to all of the rights contained in The Universal Declaration of Human Rights(UDHR)since the mid-1980s.[7]

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7 Sigrun I.Skogly, "Is there Right not to be Poor", *Human Rights Law Review*,

'The Right not to be Poor' is without doubt an important issue. The international agencies like The United Nations and World Bank are trumpeting the cause. The vital question is whether we can talk about the 'The Right not to be Poor' without addressing the question of social and political inequity that the poor suffer.

> The causes of the poverty in the country are not merely economic, and it is precisely here that we can discern the problem with extricating poverty from inequality. Consider that more than half the poor persons belong to SCs that have been socially and educationally marginalized because of their lowly position in the caste system...The significant point is that members of the so-called lower castes (and tribals) are poor not only because they lack skills and resources; they lack skills and resources because they belong to a caste that has been willfully denied such access in the past.[8]

Thus, it is clear that just giving free food, clothing and shelter will not eradicate poverty. There should be a political and social consensus in the country, that all its citizens have equal rights to common resources and to socio-political relationships. Poverty is undesirable "because it massively and fundamentally violates the basic principle of equality". "We need strategies which ensure double advantage: freedom from material deprivation as well as enabling equal moral worth."[9] If the principle of inequity and injustice are not addressed, 'The Right not to be Poor' will remain an international political game and a slogan for the vote bank. If the people in the lower rungs of the society continue to be socially marginalized, and politically considered as insignificant, then the international and national resolutions

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2, No.1, London: Oxford University Press (2002). p.1.

[8] Neera Chandhoke, "Why People should not be Poor," *Economic and Political Weekly*, Vol.XLVII, No.14, (2012):p.45.

[9] Ibid.

to eradicate poverty will be a mere rhetoric for political gain and supremacy.

> Poverty in India is the outcome of grave structural inequality perpetuated over centuries, a discriminating and dehumanizing caste system,...indifference in undertaking land reforms ...A complex issue like poverty needs holistic bold solutions from the foundational level- for instance initiating land reforms will be a thousand times better than pumping more crores into National Rural Employment Guarantee Scheme.[10]

Instead of eradicating these root causes of poverty, politicians cover up the issue by projecting the figures in crores of rupees spent in setting up feeding centres, night shelters and other facelifting programmes. Families after families in Dalit and tribal colonies helplessly watch their loved ones wasting away and dying, because of their inability to provide, even the minimal amount of food they need to subsist on. This is a paradoxical situation. India does produce enough and more food grains needed, to satisfy the nutritional needs of her citizens.

> The scarcity is due to willful systematized unjust distribution of resources. It is scarcity for the majority and abundance for minority. It is scarcity for the labouring poor and superabundance for the exploiting rich.[11]

The budgetary sessions, both at the Centre and in the States, do the balancing act of figures in their reports so that the industrialists and middle class people are at least not unhappy. Is there any one to speak for the 40% to 50% of bottom line people? It is not purely the economic deficit that causes poverty

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10 Deepu Joy, "Every Third Indian is Poor", *Indian currents* Vol. XXI, No.52, (2009): p.29.

11 Sister Agnesita, *op. cit*, p.188.

but it is the large deficit of 'social conscience' that contributes to escalation of poverty in the country. India is a major missile power, and with Agni-V successfully test –fired, India propelled itself into an elite club of nations with Inter-Continental Ballistic Missile Technology. We rejoice with our mother country for this unprecedented achievement. Unfortunately, the same country is averse to let go of its shameful, and unjust practices of the caste system which perpetuate poverty and slavishness. Neither has the country addressed, "the unpardonable sin of letting bumper crops and huge dumps of grain rot, when millions of Indians battle with endemic hunger and lack of access to food."[12]

The twin factors of caste oppression and poverty make life miserable for the poor. As a doctor, is there anything that I can do in this situation? There was no ready-made answer. I am groping, I am searching. Perhaps someday I will find an answer.

> Our hearts should never be so wrapped up in our affairs and problems that they fail to hear the cry of the poor.
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> *Pope Benedict XVI, Message for Lent, 2012*

[12] Aruna Roy and Neha Saigal, "The Politics of food for the hungry." *The Hindu*, May 30, 2012 .

6. 'Health for All' Becomes a Reality

Then Jesus answered her, "Woman, great is your faith! Let it be done for you as you wish." (Matthew 15:28)

Realization that the villages, on the whole, are left out of the developmental programmes, including health, finally forced the Government to start the 'National Rural Health Mission.(NRHM)'. This is a time bound programme for the period of 2005-2012 and NRHM is operative in 18 states of India, which have weak public health indicators and/or weak infrastructure. In this much-advertised programme,

> Every village/large habitat will have a female Accredited Social Health Activist (ASHA) - chosen by and accountable to the Panchayat - to act as the interface between the community and the public health system. ASHA would act as a bridge between the Auxiliary Nurse Midwife (ANM) and the village and be accountable to the Panchayat.[1]

What is good about the 'Mission Document' of NRHM is that

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[1] "Mission Document, National Rural Health Mission," Ministry of Health and Family Welfare, Govt. of India, 2005-2012. http://mohfw.nic.in/NRHM/Mission_Document.pdf

it has recognized the validity of the concept of 'Village Health Workers', initiated by the Aroles and subsequently taken up by many NGOs in the country. Regarding the Training of Trainers (TOT) programme, 'Guidelines on ASHAs' say:

> Existing NGOs, especially those working on community health issues at the district / block level, may also be entrusted with the responsibility for identifying trainers and conducting of TOTs.

In 1981, I was at The National Institute of Nutrition, Hyderabad, for a three months' certificate course on 'Nutrition'. As part of the field experience, it was providential that we had the opportunity to visit some interesting and innovative projects in the country. One such project was 'The Jamkhed Comprehensive Rural Health Project, Maharashtra'. Started in 1972, by an eminent doctor couple, late Rajnikant Arole and Mabelle Arole, this was the first project in the country which organised a comprehensive rural health programme, delivered through the community health workers. Dr.Rajnikant Arole received the Padma Bushan Award in 1990 and the Mother Teresa Award in 2005. He had already received the Ramon Magsaysay Award in 1979.

When I returned home, my mind was not at rest. Mobile clinics and visits to the villages and families definitely did some good. The people, especially the Dalits, appreciated the care and concern we had for them. It was also an opportunity for me to know, to learn and to experience the social realities of the people around us. However, I was not satisfied. What happened to people when they became ill on days, when we were not there with our mobile clinics? What about other villages? Even if it were a case of fever or simple injury, they had to walk miles before they could reach a clinic or a hospital. The expenses and the energy spent in these visits were another concern. What more could I do?, was the question that refused to leave my mind.

" Why can I not organize a rural health programme based on

the Jamkhed model?" I asked myself. The Aroles were a doctor couple, who had returned after their post graduate studies at John Hopkins University, in The United States of America. They had established a rural hospital, with all the basic departments and they had the required staff in position. The hospital and the community programme complemented each other.

Things were different with me and my situation. How could I, single-handed, manage the health centre and organize an entirely new programme, I asked myself. I had enough and more to do. Moreover, I did not have personnel or money for any additional programme. Why could I not be satisfied with what I was doing already? Besides, I was not sure whether people would respond to this type of intervention. Many more questions and doubts continued to gnaw at my heart.

There is a Way

Fortunately, my great desire to find a solution for the people's health problems, won over my doubts and anxieties. Slowly, ideas and plans started taking shape. In the evenings, together with some of the sisters, I started visiting the villages. I would sit down with the women and men of the village and talk about their life situation. I did not want to take any short cuts to the programme. Very often, it was the panchayat president who was contacted for implementation of any project. More often than not, he and his family would be the main beneficiaries. I wanted to avoid this pitfall, so, I went to the Dalit colonies and called the people for informal meetings. People were used to CRS (Catholic Relief Services) sponsored wheat and oil. We had stopped the distribution of these food materials, since we found people overly dependent on them, and not willing to become self-reliant and independent. They had been angry and upset at the time. Now, they thought I was going to start some such programme once again.

Contrary to their expectations, we spoke to them about their dignity and their capacity to think for themselves and to take the right decisions. Through simple discussions, they were made aware, that receiving materials like wheat and oil or other occasional benefits would not improve their lot. What they needed was some permanent solution to their problems. Just like any other group, they were tax payers to the government, and they had the right to demand, all that they needed to fulfill their basic needs. There were government schemes which were meant specifically for them. "Who will tell us about these schemes? No government official ever comes to our colonies, and keeps us informed. We do not know to read and write.", was their response.

This was the response I was waiting for. I was willing to train a person from their village, I told them, and I would prefer it to be a woman. The person would help them to go to the government offices, and get the benefits of the government schemes. She would also be their health worker. They would not have to go to far away places for treatment for their ordinary ailments, and spend the little money they earned.

The only condition was that they choose a woman, who would be interested in working for their village. She would be their worker and not one of my staff. I would not be policing them; it would be their responsibility to see that she was available and responsible for the work entrusted to her. It took 2 or 3 visits to each village to give them time to discuss, and understand the concepts that we had been talking about. I visited about 30 villages in a period of 3-4 months. I gave them a date, on which I would start the training programme. If they were interested in having such a programme in their village, they would have to send the person on that particular day for the training. There was no compulsion and they were free to respond or not.

Training of Village Health Workers (VHW)

It was 16 October 1985, the date fixed for starting the training programme. Since the choice of the health worker was left completely to the villagers, I was not sure whether they would accept my proposal. Even if they responded, what would be the quality of the women they chose? What would be their literacy level? Would they be married women or young girls? I had deliberately not given them any condition. I wanted someone whom they chose to be their health worker. It had to be the programme of the people. However, there were too many 'ifs' and 'buts' and I waited patiently.

They arrived one by one. By 9 a.m., the group was complete. There were fifteen of them; twelve of them were married; their literacy level varied from no schooling to seventh class. Thirteen of them were Dalit women and two were from the 'backward caste'. The composition of the group pleased me. Since most of them were married, they would remain in the village and continue the work. Some of them knew to read and write and this would help in the training programme. A sprinkling of non-Dalits among the participants was also good. I could teach them to mingle with one another and to respect one another. They had never attended such training programmes before, and so they were anxious and nervous. I shared with them my own anxiety of not knowing the language sufficiently well. There was also the constraint of the time factor. Together, we shall do well, I assured them.

At the outset, I wanted them to know that I was taking on this additional responsibility of training them, only because I was seeing them as representatives of their villages. Fifteen of them represented 15,000 people. Whatever knowledge they gained from this training, was to be imparted to the people in their villages. They were happy to hear this, and were ready to take

on this responsibility. There were a few other points I wanted them to be clear about: punctuality and concentration. These women were from the villages, where there were no travel facilities. They had to walk 4-5 kilometres, before they could get an occasional bus that might ply on that route. Moreover, they were married women. They had to get up very early, finish their cooking, collect water for the day and complete all other household chores, before starting for the training programme.

Usually, the villagers do not go by the clock and so they have no problem. Here, I told them, things would be different. The programme would start at 9 a.m. and end only at 4 p.m. It was an intensive training programme of a month's duration. They could not walk in as they liked. They had to be on time. We were going to talk about illness and health; life and death. So, they could not afford to miss even one word I spoke. If they missed something, they might make a serious mistake and it could turn out to be fatal. Everything had to be fresh in their memory; only then would they be able to help people in their need.

A Group of Earnest Women

To my pleasant surprise, they were an earnest group and were on time for the classes. We started a process of participatory learning. They were adults, and they had plenty of life experiences. A few simple leaflets on health, hygiene and nutrition were available in the local language. They would read together and discuss these topics. I would join them with a few comments and explanations. Then there were practical demonstrations, songs and skits. There was thorough drilling in diagnosing of simple ailments, and their treatments. Insistence was on recalling and remembering the right things at the right time. They were given strict guidelines for treating ordinary ailments, beyond which they had to refer the patients to the hospitals. Their inferiority complex gradually

gave way to self-confidence, and a positive outlook. At the end of the training programme, they were given a medical kit, which contained simple medicines, and first aid materials. We made sure that they knew how to treat the simple ailments, that were ordinarily prevalent in the villages.

The training programme included monthly follow-up meetings. These follow-up training sessions were on many practical and useful topics. We invited Ayurveda and Siddha practitioners as resource persons. Every year, these resource persons conducted a week's programme for the village health workers. They were taught the medicinal use of herbs, which were available in that particular locality. Since some of the health workers were familiar with the herbs, this was not a difficult course for them. The resource persons made sure that the health workers identified the herbs correctly, and knew the use of these herbal medicines.

"People wake me up even at night", said Kasiamma in one of the monthly sharing and evaluation sessions. People had such trust in Kasiamma, that she was their 'doctor' and adviser in time of sickness and trouble. If the sickness was beyond her expertise, she referred them to the hospitals. She also accompanied anyone, who needed to be taken to the hospital. This was the story, not only of Kasiamma, but of all the village health workers whom we trained. We trained about sixty health workers in three batches, but these women of the first batch were a highly motivated group.

Their joy and pride knew no bounds, when five of them were chosen to attend The Village Health Workers' Convention in Chennai, organized by The Tamil Nadu Voluntary Health Association. One of them, Shantha, was selected to be among the ten from Tamil Nadu to attend The National Village Health Workers' Convention in Delhi, organized by The Voluntary Health Association of India.

Pre-conception and Prenatal Diagnostic Technique Act, was enacted in 1994(Prohibition of Sex Selection Act) and amended in 2003. The reality of sex selection and female foeticide however, goes on unabated. There is no state in India, that is not prejudiced against girl chidlren. According to the 2011 Census data, in the last decade alone, the child sex ratio has dipped from 927 to 914 per 1,000, the lowest since independence. It is very unfortunate that it is the prosperous states in India that have the lowest sex ratio.

> The subjugated position of women makes them vulnerable to various forms of violence, both within and outside the family – domestic violence, rape, sexual abuse, dowry harassment and trafficking. Perhaps the most horrifying form of this gender-specific violence is female infanticide. For centuries, elders who should have been the caregivers, have used various methods to eliminate the newborn girl child – starving her, crushing her under the bed, poisoning her, burying her alive, abandoning her on a rubbish heap or street corner. What was once seen as a barbaric practice has, chillingly, now become increasingly accepted, albeit sometimes in more 'technically advanced' forms. Female infanticide has found a partner in female foeticide to give India a low sex ratio and a consistently falling female population.[2]

I have quoted this long passage from the document of Ministry of Health and Family Welfare, India, because it affirms the sad reality of women's low status in India. The document further states,

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[2] "Annual Report on Implementation of the Pre-Conception and Pre-Natal Diagnostic Techniques "(Prohibition of Sex Selection Act), PNDT Division, New Delhi: Ministry of Health and Family Welfare, Government of India.2005.

> Unfortunately, several medical practitioners have become witting or unwitting facilitators of foeticide, colluding with parents and other relatives of the unborn child to do sex determination tests. Easy, quick money was a motivation for some of them.

Once again, instead of tackling the root social problems of female foeticide and infanticide, the Tamil Nadu Government started a conciliatory but controversial 'Cradle Baby Scheme.' There are other state governments wanting to follow suit. Luckily, the social activists and feminists have levelled widespread criticism against this scheme, because it absolves the patriarchal attitudes of the parents, and gives them the licence to abandon their baby girls. The son-preference is thereby perpetuated. [3] Are we heading for a society *sans* women? The reduction in the number of women, in the marriageable age cohort in Haryana and Punjab is already creating abnormal situations for men.

Once the village health workers realized their potentialities, they were determined to educate their daughters. They were convinced that men and women, sons and daughters, were all equal in God's sight and were to be respected. When they understood that they were aborting not dead tissues, but the living foetus, they were both horrified and sad. "If we only knew this earlier, we would never have done it," they exclaimed. They could not do anything about the past, I told them. Now, it was their responsibility to teach other women to respect and protect life. "Our daughters will grow up differently; we will teach them to respect life; they will marry only after they are 21", they averred. This they faithfully did. The health workers were successful to a large extent in preventing abortions, and saving the lives of girl children.

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[3] Sharada Srinivasan, Arjun Bedi, "Daughter Elimination: Cradle Baby Scheme in Tamil Nadu" *Economic and Political Weekly* Vol.. XLV No.23, (2010): p.19.

Sight at Last for the Elderly

As their physical energy and health declined, the elderly in the Dalit families suffered much. Many of them had cataract and were going blind. In their struggle for survival, their sons and daughters could not do anything for them. The health workers told us, that it would be good to do something for these helpless people. We decided to have a cataract camp, so that the elderly did not suffer from blindness. Chengalpattu Medical College was ready to cooperate. It was a camp with a difference. The check-up and selection of the patients were done at our health centre. The cataract surgery was done in the medical college hospital itself. The health workers remained with the patients in the hospital. In batches of twenty, one hundred and sixty men and women underwent cataract surgery and were given spectacles. Every one of them regained their eyesight. Thanks to our health workers; the faces of these elderly people radiated joy and gratitude.

Eradication of Poliomyelitis

"The World Health Organization (WHO) has removed India from the list of polio-endemic countries, suggesting that the wild polio virus had been totally eliminated from the environment. ... The feat came after India successfully completed an entire year without an incidence of polio." This good news was announced in the news papers on 25 February 2012. *(The Hindu,* 25.2.2012).

At the beginning of our Community Health Programme in 1985, it was common to see polio-affected infants and children in the families. We started the immunization programme on a war footing. The health workers visited every family and made sure that all the children below five years of age, and all the pregnant mothers were regularly immunized. Within five years of the programme, no new cases of polio were detected in these villages. Later on, when the government started the Pulse Polio

programme, the health workers cooperated with PHC staff to immunize the children of their villages, as well as those of the neighbouring villages. It is a matter of pride indeed that India has become polio-free. All the same, the country has to be vigilant for another two years and more and continue the Pulse Polio programme without flagging in zeal.

A Resource Centre

These skinny, poorly-clad village health workers became the live wire of the community health programme and the news spread to other districts of Tamil Nadu. In the 1990s, religious sisters from different congregations came to stay with us for varying periods of 7-10 days, so that they could learn the secrets of the success of our community health programme. While I taught the sisters the organizational and management aspects of the community-based health programme, the VHWs taught them the practical aspects of their functioning. There were many such requests from different religious congregations of sisters. Even though we did not have proper residential facilities, we accommodated all those who wanted to learn the organization of the community health programme.[4] By then, the health workers had become experts in the use of herbal medicines. They could confidently identify the herbs, and use them for various ailments. They shared, not only their experiences as village health workers with the different groups, who came to us, but they were the teachers, to these groups, of herbal medicines as well.

The village health workers, whom we trained were ordinary housewives and daily labourers. They took on the additional responsibility of being the health workers in their villages. Their enthusiasm and dedication far surpassed our expectations. While

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[4] *New Frontiers, A History of the A.C. Mission* ,Vol VII, Bangalore : Apostolic Carmel, 2008. p.222.

the slogan 'Health for All by 2000", of the Alma Ata Declaration of 1978, remained an unfulfilled dream for most, it became a reality for one hundred villages and more of our area.

The effectiveness of NRHM is yet to be evaluated. There are a few current evaluations of this project, which "show that all is not well with NRHM. The ASHA programme in its current form has failed to generate community participation, which raises serious concern about the future of this programme."[5] Even though 'ASHA' is a modified, downgraded version of the ideal Village Health Worker and everything is not well with NRHM, collaboration of socially conscious NGOs with these initiatives of the government, will increase the effectiveness of the programme. By doing so, the committed NGOs can be instrumental in bringing health benefits to the unreachable areas of the country.

Since Christians are the leaven
we must reach out towards the masses
by providing simple, accessible
and promotional health care....
The members of the community must be
helped where necessary,
to become aware of their own problems
and to express them, so that, here again
they become the craftsmen of their own development.

Cor Unum, 1978, The Pontifical Council, Vatican City

5 Sujay R.Joshi,Mathew George,"Health Care through Community Participation, role of ASHAs", *Economic and Political weekly Vol.*,XLVII,No.10 ,2012,p.76.

7. A Healthy Foundation

Jesus called his disciples to him and said, "I have compassion for the crowd, because they have been with me now for three days and have nothing to eat; and I do not want to send them away hungry, for they might faint on the way." (Mt 15:32)

"We cannot tell people all that you have taught us." This was an unexpected response and that from Sarasa. I was taken aback. Sarasa was from Chinnalmapady village and belonged to the cobbler community. She was a typical quiet, submissive woman. But something was disturbing her. The village health workers had come for the monthly follow-up meeting and evaluation. These meetings were very important for clearing their doubts, for further inputs and for problem solving. No one missed these meetings.

I asked Sarasa to make herself clear. She went on to say that her people knew that they had to eat nutritious food and drink clean water. They would like to wear clean clothes and live in well ventilated houses.

> We need not tell them all these things. The problem is that a public water tap is available only in the upper caste area and we are not allowed to go there and get water; we get so little money for the day's work. How do we get sufficient food to

> eat and safe water to drink? This is what we want to know.

This sentiment was echoed by all the VHWs. Sarasa was only voicing, in practical terms, the sorry state of India, with regard to the Human Development Index.

Indo-Asian News Service (IANS), New Delhi, reported on 2 November 2011, that,

> in 2011, India ranks 134 in Human Development Index (HDI). This index assesses long-term progress in health, education and income indicators. The report further mentioned that India's standing is way behind scores of economically less developed countries, including the war-torn Iraq. India fares poorly in gender inequality index as well, which was 0.6, the highest in South Asia. They also mentioned that according to the UN report, India had the world's largest number of multidimensionally poor, more than half of the population, at 612 million.

I was happy that we had reached the crux of the problem so soon and so easily. Obviously, the poor were aware of their problems, but were at a loss to find solutions. This was the time to tell them, that health cannot be isolated from socio-economic problems. What Sarasa said was true. They needed to get just wages for their labour; they needed to be respected, irrespective of their caste. So, we started the sessions on 'Social Analysis'. It was not a difficult task. It was from their daily life experiences, and the experiences of millions of people like them, that the conclusions were drawn. They did not need theoretical analysis with a back-up of statistical figures. They were the living proofs of this unjust system. It was a fact that all the cultivable land of the village belonged to a particular group and not to them. They were kept under the perpetual

bondage of the caste system, which ensured that they were economically deprived and politically powerless.

The caste system is inherently bound up with the religious beliefs, so that it becomes difficult to question such an unjust system of oppression and discrimination. For the first time, they were hearing, that they did not need to accept their situation as their fate. The situation can and must be changed. Can you imagine their joy when they heard, that all human beings were created by God and, that the resources of the earth belonged to everyone? "Why then was this unjust hierarchical social system and oppression perpetuated for centuries?", they asked.

These sessions had an almost magical effect on the minds of these women. Their subservient and docile minds were transformed into a questioning and inquisitive mode of thinking. They were almost enraged at the realization, of how unjustly they had been exploited all these many years.

They knew they were paying taxes to the government, even for the little huts and small plots of land they owned. It was this tax money of the people, that paid the government teachers, nurses, doctors and all other government officials. "Then why aren't our children allowed into the same schools as the children of the upper caste? Why are we not allowed to use the wells and hand pumps of the village?" These and many other questions tumbled out of their hearts and minds. "We need to get just wages for our work, so that at least our children can go to bed without being hungry and sick."

They were ready for any action that would bring justice to them. We had to restrain their enthusiasm. "No one will listen to you as individuals, and, as individuals, you cannot represent your villages. You need to organize yourselves as a group and it will take time", we had to caution them. They went back to the villages and to their daily tasks. Their newly found knowledge

could not be kept to themselves. They started talking to women of their villages. Whether around the village well, or working in the fields, the health workers shared this 'good news', with their friends and neighbours. Some were sceptical, but others were inclined to trust the health workers. The information, the health workers shared with them made sense. They worked so hard, and yet what was the quality of their lives? They realized, that they needed to come together and discuss these matters.

No Real Achievement is a Cakewalk

It was not easy for the women to come together. The idea of women coming out of their homes, and that for meetings and discussions, was strange and even 'heretical' to the villagers. They were expected to be silent and submissive. They could not give their opinion, even in their own household matters. Men had the final word in everything, in spite of the fact that they spent most of the money, that they earned on alcohol. Women worked the whole day long, with a double burden of household work and earning what was needed for their daily living. Besides all this, the drunken husbands would attack them with sticks and knives, causing serious physical injuries and mental torture.

The health workers continued to visit the women in their families. Their own family and village situations were the springboard from which they started the discussions. They needed to walk 2-3 kilometres to get a pot of drinking water. With the meagre wages they received, they could not buy the food grains needed even for one meal to feed their families. The health workers assured them that there was a way out of this miserable situation, provided they came together and formed an association or *sangam*.

The women were convinced, but they were afraid of their men. The health workers spoke also to some of the sensible men of their village. After all, the health workers were available for the medical needs of everyone in their village. After 2 to 3 months of

continuous prodding and pleading, a few women started showing up for the meetings, but they were hesitant and afraid. The health workers encouraged them. Initially, the meetings were scheduled every week, so that the women would form a habit of coming to these meetings. With the small number of women responding in the beginning, the health workers were getting discouraged. They felt it was a thankless job. Fortunately, the monthly meetings of health workers were an opportunity to share their grievances and disappointments. We kept encouraging them.

Together for a Cause

The patience and perseverance of the health workers started yielding results. In the villages, women came together and organized themselves into associations. Unlike today, when the term, Self-Help Groups (SHGs) is commonly used, in the eighties, the associations of women were called *Mathrusangams* or *Mahilirsangams* in Tamil. "How could this be allowed? Women are supposed to be at home, cooking, cleaning and caring for children. How can women get out of the house late in the evening?", their husbands growled. Initially, many men did not allow their wives to come out of their houses, even though the meetings were held in the same village. There were exceptions, of course. The men, who knew about the health centre and its credibility, allowed their wives to gather for the meetings. Other men stood around and watched. They thought that the women would only gossip, quarrel and fight. "Can they do anything that we men are not able to accomplish?" the men mused.

"Let it be for the time being", we told the women. "When they see that you have a purpose for these meetings, and you are not going to boss over your men, they will give you the freedom needed". That is exactly what happened. When the men noticed that the women were getting better wages for their work, the sick were cared for, and the village roads and conditions improved

beyond their dreams, they allowed their wives and daughters to join the group and even encouraged them.

Meanwhile, the health workers had begun discussing the problem of low wages, and the basic amenities that were lacking in the villages. Some of them succeeded in organizing women's groups in their villages, within 5 or 6 months of their training. Others took a little longer. They supported one another and learnt from one another. The health workers, who were successful in organizing women in their villages, visited the villages of other health workers. They convinced women of the need for coming together and organizing themselves into associations.

We Succeeded

Shantha, from Vayyavoor village, was eagerly waiting for her turn to share her experiences of the previous month. "We succeeded", she almost shouted triumphantly. "In what?", others asked.

> How can we live on such meagre wages? So we, the women of our village decided not to go to work, when the landlord came to call us for harvesting the crop. Not only that, we went around all other neighbouring villages and convinced them also not to go to work the next morning. The landlord was flabbergasted, as the crops were overdue for harvesting. He could not get anyone to work. So he came in person and begged us to come. This was our opportunity to demand higher wages - and we succeeded. Is this not a great achievement?,

she asked, with great pride.

Indeed it was! There were many such incidents that they shared with one another. Such reflective sharing at the monthly meetings encouraged the timid ones, and they promised to support one another in their efforts to demand justice for their people.

Another incident, that they reported, showed how keen they were to translate their knowledge into practical action. The politicians hardly visited the Dalit and other backward colonies. If they visited the villages at all, it would be at election time. As expected, one of the MLAs turned up at a village for canvassing of votes. As there was no response or enthusiasm from the people, he asked for some water to drink. The villagers had decided what they would do. Every family brought out the empty mud pots and told the MLA, that they would give him water only after they got safe drinking water in their village. Earlier, they would have garlanded him as befitting a 'VIP' and begged for some favour. Now, no more would they beg. It was their right. It was the responsibility of the government to provide, at least basic facilities of food and water for the people.

I was proud of my village health workers. I did not have any social workers with a Master's or even with a Bachelor's degree. For that matter, I did not have any social worker at all. I relied solely on the village health workers. These illiterate and semi-literate health workers were intelligent and enthusiastic. They succeeded in organizing the village women into *Sangams*. The health workers knew that it was the training, that they had received that had transformed them into social activists. There was an inner fire burning in them, the fire enkindled by the awareness of the injustice, oppression and poverty that they had suffered for centuries, and the desire to overcome the situation at any cost.

They requested us to organize such training programmes for the members of the *Sangams* as well. There were already more than fifty *sangams*. We could not backtrack now. We started village-wise training programmes for women. Forty to fifty women from every association came for the two days' training. This programme was spread over two years from 1987-88. Thus, the village health workers succeeded in building up very active, powerful *Mahilirsangams*.

Believe it or not, these health workers were not working for salary. All they received was Rs.100/- per month, which was not sufficient even for their bus fare. Working for a cause and working for the people gave them a satisfaction which they had not known before.

Doctors and Nurses were not Spared

"What is the name of the nurse who comes to your village?", I asked the village health workers, again during one of the regular meetings. "Nurses! Doctors and nurses never come to our colonies. We only see them drinking tea in the Panchayat President's house", they replied. "It is not my responsibility to carry out the immunization programme in your villages. There are doctors and nurses who are paid for this job". I told them. The homework for the month was to find out, where their respective Primary Health Centres were, and the names of the nurses and the doctors who were supposed to come to their villages.

They returned triumphant once again, because they had done their homework. The representatives of the women's associations went to their respective Primary Health Centres. "Who are you to ask us to come to your village? Get out of this place," was the rude response of The Primary Health Centre staff. The women calmly replied, "You are paid your salary from the tax money of the people. That is why you are called government servants." The doctors and nurses were stunned. They knew that they could not dismiss these women as ignorant. "We have not come to fight; we want only your services. The children need to be immunized, pregnant mothers need their regular check-up and the sick need treatment. Tell us the day and time when you will be at our village," said the women firmly.

The Primary Health Centre staff started visiting the Dalit colonies. They carried out the immunization programmes regularly and treated the patients, who needed more professional handling.

The health workers were always there to help them to sterilize the needles and to see that all the children and pregnant women of the village were immunized as per schedule. The doctors and nurses found that these village health workers were intelligent, with sufficient knowledge of the ordinary ailments and their treatment. So, they entrusted the medicines needed for the primary health care to the health workers. The Primary Health Centre staff could not make daily visits to every village. The Village Health Workers would hold the fort until their next visit.

Neither Could the Teachers be Absent

The daily scene in village schools was amusing. On most days, the teachers would be absent the whole day. On other days, they would come around noon, and when they came, they would rest and relax, in whatever way, and whichever place possible around the school. All this would happen in full view of the children and parents, and no one would question them. After all, they were teachers, next to God ! This was one more situation that cried for change. And the VHWs were ready for it.

Alancheri is a village only 10 kms away from Uthiramerur town, where the Assistant Education Officer had his office. Yet, the teachers would be regularly absent or late, or into businesses other than teaching. One day, Mangalakshmi, the local VHW, along with her women's group, waited and met some teachers, who were arriving at the school around noon. The women stopped the teachers and asked them to go back. "We do not want teachers like you. If you want to work in our school, then come on time and teach our children well." This was an utterly unexpected action, but had the desired effect. Not only the teachers of that village school, but also the teachers of neighbouring villages started coming to school on time. The news of the determination and power of the women was spreading to other villages.

The women were happy that their children were at school and were getting educated. They were sad, that they themselves had not been able to go to school in their childhood. They expressed their desire to learn now and to be literate. "This will help us to go to the government offices without fear, and to read and to sign the letters and documents intelligently", they said. It made sense. We were more than willing to fulfill their dream. In 1993, we approached the State Resource Centre (SRC) for non-formal education. They were only too happy to help spread literacy among the village women. SRC trained a core team, comprising semi-literate and literate village health workers and *sangam* members. 'Each one teach five' was the motto given to the core team. They were given the literacy kits required for the purpose. So, in the evenings, the villages came alive with literacy classes. The core team members were generous with their service. Each one taught not only five women of their obligatory quota, but extended their service to all those who wanted to learn. SRC supplied the additional kits needed for the purpose. Not less than two thousand women were made literate through this programme.

Drinking water, sanitation, medical care, education and livelihood are the foundations for good health. These basic facilities are the rights of every citizen of the country. It is unfortunate that the poor have to struggle, demand and even fight for these amenities, so that they can live a decent, healthy life. Training of more doctors, and increasing the number of hospital beds will not make people healthy.

> At the root of ill health is an iniquitous and unjust distribution of the means to health. All health programmes must therefore be an integral part of human development and poverty alleviation programme. Only constant pressure from the representatives of the poor can ensure that this focus is retained.[1]

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[1] *Health for All Now,* The People's Health Source Book, 2nd ed.,The National

Sarasa was intelligent to know, that people could not enjoy health without simultaneous improvement in the socio-economic conditions of their life. They came together; they struggled and achieved their purpose to some extent. Healthy living needs a healthy foundation of purchasing capacity and social equality. Without political will, social equality and social justice will remain elusive dreams for the poor.

> If all men are equal, then all men are of the same essence, and the common essence entitles them to the same fundamental rights and equal liberty... In short, justice is another name for liberty, equality and fraternity.
>
> *Dr. B.R. Ambedkar*

Coordination Committee for the Jan Swasthya Abhiyan,(People's Health Movement- India) 2004. p.356

8. Women: Natural Activists

The kingdom of heaven is like the yeast that a woman took and mixed in with three measures of flour until all of it was leavened. (Matthew 13:33)

The health centre was crowded. Just outside my window, a group of women were talking loudly. I was annoyed at this disturbance. Fortunately, I decided to ignore the sound. They had to wait for their turn for consultation, and what else would they do but talk. I heard a familiar voice and I listened. The woman was from one of the neighbouring villages. She was speaking to the women who sat around her in rapt attention.

> I have not been to a school. I am a cobbler woman, (one of the lowest of Dalit sub-group). Today, I am able to approach the government officials including the District Collector without any fear. None of our families had the ownership of our land. The women's association of our village managed to get *patta* (ownership deed) for all our families.

There was pride in her voice and rightly so. She was the President of The Women's Association of her village. And what do you think was the response of the women who listened to her? "Please come to our village and speak to us. We also want to organize ourselves and improve our situation".

Was it not a matter of great joy and satisfaction for me to know, that these illiterate women were empowered to such a degree, that they were able to encourage and teach the women of other villages?

Free of Debt Trap

Muniamma had tears in her eyes. She looked very anxious. I asked her what the matter was. "Where will we go? Tomorrow the moneylender will come. He has given us the ultimatum. My husband has gone to the landlord to ask for a loan so that we can pay the moneylender. We have to pay the capital with the interest accumulated." This was strange, I thought. To repay a loan, they had to take another loan and a bigger amount at that. She further explained to me that they took this loan a few years earlier, when her husband was sick and had to be hospitalized. They work very hard in the landlord's house, but the little money that they get as wages was not even sufficient to buy food for the family. This was a sad story. She sent her three children to the village school. They kept asking her to buy a set of decent clothes, but she was not able to buy anything for them. She also whispered that her husband needed to buy some liquor every day. "Otherwise how will he work? He works very hard."

The women in their training sessions poured out their woes. There were plenty of reasons for their poverty and for their inability to free themselves from the shackles of poverty.

- They work hard, but work for a landlord, who sucks their sweat and blood
- He pays them most unjust wages.
- The hard physical labour tires them so much, that liquor is a customary pain reliever for most men folk in rural India and liquor is expensive.

- The poor are then forced to borrow from money-lenders or landlords and end up as bonded slave workers.
- It's a vicious cycle of poverty begetting poverty.

This enslaving chain must be broken and the women understood it very well.

In their precarious living conditions, any unforeseen or additional expenses like ill health, weddings, any other celebrations, and even death, drove people either to the moneylenders or to their landlords. With their constant struggle for survival, they were unable to pay back even the interest. Finally they were forced to sell whatever little they possessed. Borrowing from the landlords for whom they worked, made them bonded labourers which meant, that for generations the family remained bonded to these unscrupulous land owners. The whole family, including children worked for the owner. The poor people had no right to question the unjust wages they received, and there was no record of the loan paid back.

That was when we decided to give the women the input on 'small savings scheme'. It highlighted in practical terms, the amount of money that was usurped from the individuals and the villages by the moneylenders and the landlords. The trainers made simple calculations and revealed, that entire villages were losing staggering amounts by way of paying interest to the moneylenders. The trainers challenged the women as to how they can be free from poverty, if they lose so much money to the moneylenders year after year.

This information was so convincing that they decided to start the small savings scheme. Every one had her own note book, where she entered the amount she contributed, and the treasurer of the association would countersign it. The families were very happy when they realized that in case of necessity, they could take their

own savings or if more money were needed, they could borrow from the association at a very low interest rate. That was when the men started respecting their women. The health workers reported, "We have not seen the moneylenders for months in our village. We will not allow them in our village again."

A Pragmatic Approach

Women were ready for action. They had the knowledge of social analysis and social action. However, how long will they and their families go on with hungry stomachs and empty pockets? People needed some props to improve their socio-economic condition by augmenting their income. Social Action Movement, our partner organization introduced some cooperative schemes. Each village group discussed and decided the type of economic programme, that would be viable in their villages. Whatever be the programme they decided upon, it had to be organized as a cooperative. The objective of the scheme was to cement the groups together, and to promote collective thinking and decision making capacity. It would also bring some additional income to the families.

It was mostly the women's associations that came forward with practical ideas and suggestions. They consulted the whole village in deciding the programme. Some associations decided upon cattle rearing, others started petty shops in the villages, and still others suggested the renting out of things needed for weddings and celebrations. Whatever it was, the decision was theirs and they had to manage the whole project among themselves. Most of the groups managed these cooperative ventures fairly well, with the exception of one or two groups, who failed to work together. The profit from these programmes was added to their savings. This experience gave them confidence to manage their own business affairs. They were becoming self-reliant, and a people of positive attitudes. Unlike microfinancing and microcredit system

which is much trumpeted today, here the emphasis was on empowering the people financially, by enhancing their income and their purchasing capacity.

Microfinance, when started by Prof. Muhammad Yunus in 1972 in Bangladesh, and later on, when he established the Grameen Bank, it really fulfilled a great need of the poor people. He was honoured with the Nobel Peace Prize in 2006. However, when the unscrupulous financiers use the concept for profit purpose with market approach, people are caught in the debt trap. "Small loans add up to lethal debts. The microfinance industry pursued a path of rapid business growth in recent years; two investigations now link it to debtor suicides." This was the headline of the first page of *The Hindu* on Sunday 26 February 2012. We need to be aware of this debt trap into which the poor can be pushed.

Barefoot Lawyers

Rural women have other problems too and often more severe than financial problems. Violence against women is the most common of all types of domestic violence. One of the reasons for it being so prevalent, is the patriarchal mindset of the society, that women are physically and emotionally weaker than males. Though women today, have proved themselves in almost every field of life, affirming that they are no less than men, the reports of violence against them are much larger in number than against men. The possible reasons are many and are diversified over the length and breadth of the country. According to The United Nations Population Fund Report, around two- thirds of married Indian women are victims of domestic violence, and as many as 70% of married women in India, between the ages of 15 and 49 are victims of beating, rape or forced sex.[1] The tragedy is that

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[1] Ankur Kumar, "Domestic Violence in India: Causes, Consequences and Remedies", Youth Ki Awaz, 2010. .youthkiawaaz.com/domestic-violence-in-

domestic violence happens within the intimate atmosphere of the family, and it is kept secret even though it is brutal. Tulsidas' saying: "Drums, donkeys and women need to be beaten", is literally practised in Indian households. Insistent demands from social activists and feminists resulted in passing the bill 'The Domestic Violence Act, 2005' by the parliament. Until this Act was passed the victim was at the mercy of the abuser. Of course this bill not only safeguards women, but also anyone who is a victim of domestic violence, regardless of gender and age.

Sexual violence and rape are problems, that traumatize women, not only physically but destroy the entire psychology of women.

> Rape,... is an expression of gender-based inequality in that it reflects upon the woman characteristics of "vulnerability, and violability," while it attributes to the men the power of "forced intrusion." The end result stigmatizes the woman. Thus, rape, as per MacKinnon, is a punishment for being female.[2]

The upper caste men humiliate and torture Dalit men by raping their wives and daughters. The *panchayats* and the police are there only to safeguard the privileges of the upper caste people. In fact, Dalit women suffer a double share of oppression, both as Dalits and as Dalit women. Men with power and money take vengeance by raping women of their rival group or the group whom they want to teach 'a lesson', as happened in Gujarat during the communal violence of 2002. Do not our hearts recoil and minds troubled, when we hear of tiny tots, as young as two year old girl children being raped by ruthless men? It is daily

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2 Amrita Sinha, "The Concept of Consent in 'Date Rape' Feminist perspectives on the law relating to acquaintance rape" in *Gender, Human Rights and Law*, Vol I ed., Sarasu Esther Thomas, Bangalore: National Law School of India University, 2011. p.80.

news that helpless women, with disabilities such as visually and hearing impaired, and with intellectual disability are raped. We tend to become insensate at times with such everyday occurrences. We need to empower women against these atrocities and violence.

We joined hands with the socially conscious lawyers. They had a simple curriculum for training the oppressed people on the basics of the law. As part of the ongoing training of the health workers and the women leaders, we organized regular legal training for them. Batches of forty women from the villages came for two days' training. The women were happy to know that the police could not treat them as they liked; a woman police had to be present in case of arrest, and that they could not be taken to the police station at night. They learnt to file FIR and many other basics of the criminal law. They were also given knowledge of those sections of the law pertaining to women, rape, marriage, divorce and property rights. Nothing that the health workers and the women learnt remained only on paper, or as mere theory. They had plenty to report during the monthly meetings. Women in the villages brought their problems to the health workers and association leaders.

I must admit that, these women were now more confident and knowledgeable than I. While they attended these classes, I had to be available to my patients at the health centre, who came from long distances. However, I was proud of the health workers, and women of the villages. From their helpless and hopeless situation, they were being transformed into a confident, a courageous and an empowered group.

Networking is Power

Women were ready for action, but they needed the support of a larger group. It was all right for women of an individual village to demand water, and other basic facilities for their own village,

and there would not be much of a problem. However, larger and complicated issues like inter-caste marriage, and oppression of men and women by upper caste people, needed organized struggle on a wider scale. As an individual NGO, our sphere of activity could be limited, but when joined hands with like-minded groups, our dream of establishing a just and egalitarian society could be fulfilled, where the voice of the poor and oppressed would be heard and listened to. My responsibility to the patients did not allow me to be a full - time social activist. I had trained the health workers to be social activists. They needed guidance and support to go forward with their plans.

Fortunately I was associated with a NGO, 'Social Action Movement,' (SAM) Mamandur, Chengalpattu. As part of building up of various people's organizations, SAM organized women's associations into a federation and named it *'Mahilir Sakthi'* (Women Power). As President of SAM, I decided to cooperate fully with this organization. Women's associations, which we had initiated as a part of the community based health programme, from then on became a part of this federation. We would continue to work together.

Now We Know What to Do

The members of *Mahilir Sakthi* were very often approached by the village women with their problems, especially that of domestic violence and rape. The federation leaders would go to the concerned village and hold meetings with both the parties. These women leaders had the wisdom to analyze the situation, propose solutions and they also saw to it that these suggestions were implemented. Many were the cases that were referred to them and problems peacefully settled. In case of resistance from men, these women registered cases in the police station and sought legal intervention. "Now we are not afraid, we know what to do", they said. It was much before The Domestic Violence Bill was passed!

Kamala was married only three years ago. They had no children. Her husband Raghu and his parents harassed her continuously. Initially it was only verbal abuse and insults. Later on, she was beaten daily and was being tortured. Her parents told her that it was her fate and they could do nothing about it. One day, when no one was in the house, she managed to escape, and told the members of *Mahilir Sakthi* of what was happening to her. The women visited the family and spoke to Kamala's husband. They explained to Raghu and her parents, that conceiving a child did not depend on the woman alone. The man was equally responsible, and both of them needed to go for medical tests.

Raghu and his parents would not listen. The problem continued. The women returned. This time they told Raghu that beating his wife was a crime, and that they were going to register the case at the police station. The family did not believe that they would register the case, but the women did. Raghu was surprised and shocked when the summons came. He begged the women to withdraw the case, and that he would do all that they asked him to do. Only when the women saw that Raghu was serious and stopped the violence against his wife, did they withdraw the case. Raghu and Kamala went for a medical check-up. After all it was Raghu who was responsible. He had a very low sperm count.

An Ambulance for a Social Sickness!

It was 1 a.m. There was a knock at the convent door. I thought it was the usual medical emergency problem from some village. When I opened the door I realized that the problem was different. A group of youth stood there, anxious and impatient. The forest department in the name of afforestation, was determined to take over the land, which people were cultivating for years. It was good agricultural land, with a lake providing water for cultivation. However, it belonged to the government. If the

forest department took over this land, these poor people would be deprived of their livelihood. It would mean starvation and malnutrition.

People somehow or other got wind of the news, that the forest officials were determined to plant trees on this vast stretch of land, and that they would begin the work next morning. There was no time to waste. They had to act immediately. They needed to go to as many villages as possible and inform the people about the situation. For this they needed a vehicle. There was no other vehicle in the area, except our ambulance. This was truly an emergency, and so I asked them to take the ambulance and carry out their plan as shrewdly as possible.

A large crowd of women and men gathered at the police station at 5 a.m., and demanded that they stop the forest officials from planting the trees. The police personnel were taken aback at this demonstration of their strength, and at the clarity of the thoughts and ideas expressed. They had never seen Dalit population of the area demanding any thing like this. The police had no other choice, except to inform the forest department of this situation and ask them to stop their plan of planting the trees, at least for some days.

Once this was achieved, they went to the District Collector and demanded, that he allow them to cultivate the land, that they were cultivating for years. They had no alternative means of livelihood. Initially a stay order was given, and after a protracted struggle, the people succeeded in stopping the forest officials from planting trees, and taking over the land. The success was due to their alertness and organizing capacity. Earlier people would have taken it as their fate, but now they knew what they had to do .There was no need for any one to tell them what to do. I had a reason to be proud, because our ambulance had an important role in this victory!

Many were the protest meetings and rallies, that were held so that the government would be forced to take notice of the rights of women, tribals, Dalits and other weaker sections of the society. The landlords could no longer go scot-free after raping Dalit and tribal women. People would not give up their resistance until the government officials and the police took action, and arrested the offenders. Going for these protest meetings and processions, meant that these poor people had to forego their daily wages, and face even the threat of not being employed again. Yet, they were ready for these protests and show of strength. The binding force of people's movements, whether Dalits, tribals, women, agricultural labourers, cobblers or dhobis, was the hope that they would be recognized as human beings with equal rights. For this they were ready to struggle, protest and even fight because they were demanding only what was lawfully their right.

Women and Men as Equal Partners

In the last two decades women have proved their worth as panchayat presidents, and as members of the local governing bodies. The 74th Amendment to The Indian Constitution, 1992, provided for one- third reservation of elected seats for women at local government level in urban and rural areas. There was also a one-third reservation for women for posts of chairpersons of these local bodies. Their participation in the Women's Associations and Self-Help Groups, had already prepared women to take their rightful place in the local governing bodies. Even though there was stiff resistance from men in implementing this Constitutional Amendment, women stood their ground and they are proving that they are ready to be equal partners with men.

It is against this background of increasing the participation of women in public sphere, that The Women's Reservation Bill was introduced in the Lok Sabha in 1996 as the 81st Constitutional Amendment Bill. Contrary to the high expectations raised by

the introduction of this Bill, the parliamentarians of one of the world's largest democratic countries in the world, have found ways and means to stall the discussions, and passing of this Bill. Cutting across party lines, the male chauvinists are dissecting and fragmenting the Bill, along caste and political lines, that even on a later date, if the Bill is to be passed, it will only be a caricature of the original. Men, surely will not easily give up their supremacy in the political arena. Will we ever achieve the goal of equal participation of women and men in this democratic country?

> In Indian society, gender equity goes against the grain of our patriarchal traditions, which overtly or covertly resist any change that challenges them. Only vigorous politics for gender equity can challenge our male dominated electoral politics. The Women's Reservation Bill is largely being pushed by women MPs. If there were more of them in the house, there would surely have been a very different debate from the one that stymied it in caste and patriarchal politics.[3]

On one particular day, I was busy as usual with the patients at the health centre. The members of the women's group from Palliagaram village came to call me to join their protest meeting and rally. I asked them what the problem was. "We are not getting water in our Dalit colony. The problem is going on for some days. Unless we protest, they will not do anything. Please come and support us", they said. I was happy that the women had organized the programme all by themselves. However, I feigned indifference. I told them to get all the men of their families to join the protest. Water was needed not for women only, but for the whole family. "I shall come only if the men also join the protest",

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[3] Rudi Heredia, "Holding up Half the Sky: Reservation for Women in India ," *Economic and Political Weekly,* Vol. XLVII, No.9, (2012):p.53.

I said. Women convinced their men of the need for joint action, so men and women of the Dalit colony joined hands for the cause. When the officials saw that the entire Dalit colony, men and women stood together, they knew that they had to heed to the demand of the people.

I am a feminist. The Village Health Workers and the members of *Mahilirsangams* were feminists. Feminism is an awareness of women's oppression and exploitation in society, at the place of work and within the family, and conscious action to change the situation. A feminist is any one, woman or man who recognizes the existence of sexism [discrimination on the basis of the gender], male domination and patriarchy, and takes some action against it.

Women needed to become aware of this discrimination and exploitation. The training programmes for women were designed for this very purpose, of awakening the feminine genius within them. This awareness catapulted them into feminists, and social activists. However, we were neither radical feminists nor anti-men. All that we were demanding was equal partnership and equal rights. The women had already the triple burden of never ending domestic work, working hard as daily labourers and looking after the children and the old in the families. Now they had the additional burden of attending the meetings, rallies and processions. I did not want women to bear this additional burden without the support from men.

Improved wages and savings of the family gave some security to the families, and there was the tendency on the part of men to abdicate their responsibility for their families. We wanted men as equal partners in domestic work, as well as in shouldering family and social responsibilities. Women discussed these matters during their meetings. They formulated their own strategies, as to how to rope in their men in household work, just as they were involved in earning an income for their families.

People, including women perhaps enjoy the jokes and proverbs that belittle women. Women are branded as gossipers, and tale mongers. The village health workers and *'Mahilir Sakthi'* disproved these stereotyped expressions. When they are given equal opportunities, women are second to none. They were becoming a power to reckon with.

> And I tell M. Elias to hold on and to stand firm for her lawful rights, as our Mother St. Teresa did, who when necessary stood against bishop and provincial; and I add to Mother Elias, "there is nothing a man is obliged to respect more than an undaunted woman who fearlessly and respectfully maintains her lawful rights and stands her ground without flinching.
>
> *Mother Veronica in her letter of September 20, 1899*

9. Livelihood and Land Issues

I have observed the misery of my people who are in Egypt; I have heard their cry on account of their taskmasters. Indeed, I know their sufferings and, I have come down to deliver them from the Egyptians, and to bring them up out of that land to a good and broad land, a land flowing with milk and honey...(Exodus 3:7-8)

Someone rushed into the crowded health centre and whispered in my ears, "The police in plain clothes have surrounded SAM office." (SAM stands for Social Action Movement, a well known NGO of Kancheepuram District of Tamil Nadu, known for its activism in the issue of the land rights of Dalits). It was the year 1994, and to be precise, it was 1 p.m., on Saturday, 8 October. I understood the situation. SAM had taken up the issue of *Panchami* land. The land issue is, naturally a food issue and, consequently, a health issue. How can the people be healthy without food, land and water? So, I was concerned.

For the benefit of those who do not know what *Panchami* lands are, here is a brief information about them. These lands are known in the Revenue records as DC lands or Depressed Class Conditional lands. Knowing the helpless condition and poverty of the Dalits, the British Government had allocated some cultivable lands to them in the 1930s, in different parts of India. Since there was widespread concern, that these allocated lands could also be grabbed by the upper caste people, the British Government had

issued special orders, regarding the sale and purchase of these lands. The Government order said, that these especially allocated DC lands should not be sold or bought by any others, except the Dalits. Their ownership could be passed on only to the Dalits, and even then, only ten years after the original assignment. Thus, for many decades, the Dalits were in possession of these DC lands. However, they were unaware of the laws and rules regarding these lands. Taking advantage of the ignorance of the Dalits, who owned such lands, the rich and powerful, the bureaucrats and politicians, grabbed these lands from the Dalits for meagre prices.

The law also said that such DC lands, if they were found sold or bought against the laws, would be taken over by the government and restored to their original owners. The land rights NGO, SAM, had come across, by chance, many hundreds of such DC lands in the hands of upper caste persons, in total violation of the special laws pertaining to them. SAM decided to act on this issue. To take the issue easily to people, SAM renamed the DC lands and called them *Panchami* lands, so that the Dalits would feel affinity with them, as they themselves are known as *panchamas*.

Karanai village, near the famous Mahabalipuram tourist centre in Kancheepuram District, was one such place, where around 650 acres of *Panchami* lands were available, but in the illegal possession of some non-Dalits. One Deepan Chakravarty of this village, came to know by chance, that lands belonging to his and other families in his village, were, in fact, *panchami* lands and that they had been subjected to a huge fraud. Karanai village being close to the Mahabalipuram tourist centre, the land prices were very high.

Deepan decided to fight for their land rights. Initially, he went through the normal channels, available for addressing such grievances. He approached the concerned government officials, including the District Collector. Since very powerful politicians

and government officials, including a local IG (Inspector General of Police), were part of this fraud, no one dared to get involved in confronting the situation. Months and years dragged on. Deepan was getting frustrated. He came to know about SAM and decided to approach them.

SAM studied the facts and figures of *Panchami* land thoroughly, and consulted good lawyers. The lawyers were helpful in obtaining the copy of various land mark judgments concerning *Panchami* lands. Once Fr. P.B. Martin, the Secretary of SAM, and other collaborators were convinced, that this was an important issue of land and livelihood, they decided to support the cause.

Struggle for Land Rights

What followed was an unprecedented struggle for the land rights of the Dalits. The normal channels of obtaining justice failed. So, they decided to take recourse to political action. They decided to go as peacefully as possible. As a first step, early in the morning of 5 October, about a thousand Dalits and their leaders went to Karanai, and installed a statue of Dr. Ambedkar on the land in dispute. No one opposed this ceremony at that moment. By evening, however, the police broke the statue into pieces and removed it from the place. This insult to one of the great Dalit leaders of the nation, and the Father of the Indian Constitution (as he is commonly known), was too much for the Dalits to bear. Deepan and other Dalits protested. The police arrested Deepan and fifteen of his friends and sent them to jail.

The police did not stop with this. They had orders from the high places to crush the effort of these poor Dalits. They knew that, without the support of some socially conscious group or organization, the Dalits would not have been able to organize such an action. Their search led them to the office of Social Action Movement, Mamandur. They wanted to arrest Fr. Martin, the Secretary of SAM. Fortunately, they did not know the priest

personally. While the police were searching the office, some friends of SAM helped him to escape from the office. At that moment, people needed him, not in the seclusion of prison but outside, so that he could make public, the truth about the *panchami* land. It was a miraculous escape indeed. He managed to circulate the news of this land struggle to all the important newspapers in Chennai.

Health Centre, a Refuge

Now that Fr. Martin and the leaders were either arrested or in hiding, the staff and the people needed support. As president of SAM, I was supposed to give them leadership. That was the reason why they had brought the news to the health centre. The ambulance of the health centre was a great help in these situations. The police were still there, but they would not suspect an ambulance. The local people also supported us, saying that it was the usual ambulance, which took the sick people to the hospital. Since the police could not find Fr. Martin, they were furious. They threatened the staff, beat up some of the staff members, ransacked the office records and finally left the place.

Amidst this confusion and anxiety, John Thomas, one of the staff of SAM, stepped forward and made a prophetic statement, that they were not going to be cowards, but fight like brave people till the cause was won. Did he have any inkling, that he would be laying down his life for the cause within two days? He spoke to all those who were present there and said, "The protest meeting was planned for 10 October. This is our struggle. The authorities have arrested the leaders. Now we will take the struggle forward." Even today, I can picture his face as he said this, calm but resolute.

From then onwards, it was a flurry of activities, but secret and subdued. The news had spread to the villages, that SAM office had been surrounded by the police and naturally, they might

conclude that the protest meeting had been cancelled. So the staff and the leaders had to work all the harder. We had only one day left for the programme. Fortunately, the systematic planning had already been done. Only, the people had to be reassured. The people had attended many protest meetings and rallies and so it would not be a problem.

9 October being a Sunday, I was free to involve myself fully and so, once again, with the ambulance we went to the villages and assured the people and encouraged them. We knew the police would arrive at any time. Even the health centre was not safe. We chose some deserted, interior, lonely, bushy areas for our meetings with different groups. SAM staff, including John Thomas, had made it a point to contact every village and personally meet the people and answer their queries. Finally, everything was ready. Everyone knew their duties and responsibilities. It was past midnight and the staff did not go home. SAM office was not safe for them to rest. Naturally, they turned up at the health centre. We gave them a room; they were exhausted with the day's work and slept peacefully. Most of them were up by 6 a.m., but John Thomas was still sleeping. I had the painful duty to wake him up to face the day, the day that robbed him of his life. When he was ready to leave, he came to me again and asked me to pray for him.

Monday, 10 October 1994

By 9 a.m., about 5,000 men and women had gathered in front of the Sub Collector's office at Chengalpattu. It was a peaceful demonstration. A group of ten people, including three lawyers and Dalit leaders, met the Sub-Collector and submitted a memorandum. However, the sub-collector was not ready to talk to these mediators and representatives of the people. On the contrary, he insulted them and asked them to get out of the office. Later on, some of the media personnel approached the Sub-Collector and requested him to meet

the representatives of the people. They also reminded him that it was a Monday, when he was supposed to listen to the grievances of people, but he still refused to meet and talk to the people's representatives. It was already 2 p.m. People started losing patience. Some youth threw a few stones at the office building. Some rowdy elements made use of this confusion and burnt a government bus.

All of a sudden, the police opened fire. This was unexpected. There was no warning; there was no lathi charge, no tear gas and no rubber bullet shooting. The police started shooting straight at these unarmed poor people. Many women and men were wounded. They were chased for about 10 kms. They tried to escape to the surrounding hillocks. Meanwhile, some of the youth group withstood the police atrocities bravely, and suffered serious injuries. The police must have noted the bravery of John Thomas and Ezhumalai and wanted to get rid of these young and leading activists. Both of them were shot at close range in the chest and neck. About fifty women and men were seriously injured. About 125 people, including 20 women, were arrested. The police atrocities continued till 10 p.m. and no one could go closer to the scene to help those who were wounded and dying. Thus, John Thomas and Ezhumalai became part of the history of the struggle of Dalits for their land rights.

The Police Chase

It being Monday, I had a heavy OPD at the health centre. As soon as I finished treating the patients, I was on my way to Chengalpattu to the place of the protest meeting. When I reached the SAM Office, people stopped me and asked me to proceed no further, as the police were shooting at random, anyone they saw on the way. Within a few minutes, some women who were wounded in the shooting and had managed to escape, reached the office. They had run a distance of about 10 kms and were exhausted.

They needed treatment and their wounds had to be dressed, but there was no time to lose. The police were chasing them, so, together with the women, I got into the ambulance and asked the driver to drive in the opposite direction. We could see in the rear mirror that the police vehicle was close on our heels. As we were nearing the Bukkuthurai junction, where the road turned to our health centre, I had the presence of mind to tell the driver to go ahead and not turn towards our health centre. We heaved a sigh of relief, when we saw the police vehicle turning to the health centre, which was only 5 kms away. We were happy that we had given a wrong clue to the police. We drove for about 25 kms more, and then returned to the health centre by another road. The police had gone to our area and, not finding anyone, had turned and gone away. If we had taken the usual road, we would have been taken into police custody that day. For the next three weeks, Chengalpattu town and the surrounding areas looked like an enemy territory. The reserve police, carrying guns, lined the roads.

From then on, my time was divided between treating patients and working with the court and the lawyers. All the staff members of SAM and the leaders were in jail. I had therefore, to shoulder the responsibility of handling this case. Even after 15 days, the court did not grant bail to those arrested. Families were worried and anxious, because not even their women were released. The people were at our place everyday, waiting for their relatives to return. We could only comfort them and assure them of speedy action. It took another ten days before the court finally relented and granted bail to those arrested.

These struggles, whether Dalit movements or tribal movements, have made it clear that their demand is ownership of land and nothing less. These movements see land as the only path towards a long term survival of the community. In today's context, a demand for ownership

of land by any marginalized community inevitably faces severe forms of state oppression.[1]

After the incident of 10 October, the police would come daily to our area and observe the activities of our centre. I pretended not to see them and concentrated on treating the patients. This went on for some days. The neighbours were worried and told me not to come out at night to treat the emergency patients. "Sister, please go away from here and save yourself, they will surely come for you", was the plea, not only of the neighbours, but also of the people of the neighbouring villages. I asked them, how I could think of escaping from the situation, when their relatives were arrested and were suffering in prison. "After all," I added, " I have no family. I am here only to serve God and his people. I shall do it till the end." Later on, the local police came to me and said that the police were given orders, by higher authorities to arrest me and others who were involved in this land case. Fortunately, these police personnel, who had the orders, were from outside and they did not know me. The local police did not betray me. "We are with you", they said.

The fear and panic created by the police shooting and imprisonment did not last long. People were determined to continue their struggle. The Dalits and the NGOs, who supported their cause, became aware of the problem of *Panchami* land. Protest meetings and rallies were organized all over Tamil Nadu and the neighbouring states. They organized a huge rally of more than one lakh people in Chennai on 19 November 1994. They condemned the police atrocities and the killing of innocent, helpless people. The memorandum submitted to the government demanded, that the land be given back to its original owners and the statue of Dr.Ambedkar, which they had

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[1] M. S. Sreerekha, "Challenges before Kerala's Landless:The Story of Aralam Farm," *Economic and Political Weekly*, Vol. XLV, No.21, 2010 : p.56.

demolished, be re-installed. If the government did not re-install the statue before 6 December 1994, the birthday of their great leader, the people said, they themselves would do it, as they had done earlier. The government was not ready to listen to these demands. At the same time, they knew that the people were serious about their demands. So, on 4 December 1994, they arrested most of the leaders, including Fr. Martin. After a week, they were let off, on conditional bail, and sent out of Kancheepuram District.

The Ambulance Did It Again

Whenever a rally or any other programme, connected with this land issue, was announced, the police would block the Bukkuthurai junction to prevent people, of our area attending these meetings. The police would check people, including those travelling in the public bus, and intimidate them. The people were forced to get down and go back to their villages. The ambulance of our health centre, fortunately did not display the name of the hospital and the place to which it belonged. So, no one suspected it. It is my experience that God is always on the side of the oppressed. Whenever I needed to cross these barriers and participate in these meetings and rallies, the good God sent me patients who needed to be taken to Chengalpattu Medical College Hospital. I would accompany the patients and cross the barrier. It was a sign for me, that I should not hesitate to participate in the struggle of his people.

On one such occasion, there were more than fifty policemen at the junction and they had barricaded the road completely. I needed to cross the blockade to attend the protest meeting at Karanai. I did not bat an eyelid and kept a straight face. I had children with disabilities on my lap and I was in the front seat of the ambulance. We had the ambulance light on and were driving at full speed. When the police saw the ambulance light flashing, they just made way for us and we passed safely and went for the

meeting. Since the police had blocked all the roads leading to the venue of the meeting, people from the villages could not attend it. Finally, there were more policemen at the venue than people present. With a limited number of people for the meetings, we could not escape the cameras. After a year, they caught up with us. Fortunately, by that time, all the cases had been withdrawn and we were safe. The secret service police came to the convent and asked us how we reached the place of the meeting, in spite of all the barricades they had put up. We answered gently that we did not do any harm to anyone and only helped the poor people in their need.

The Aftermath of the Struggle

Social Action Movement, being an NGO, could only play a limited role in this major struggle. As was only right, it handed over the leadership of the struggle, for land rights to the Dalit social and political outfits, in Kancheepuram District, Tamil Nadu, who carried on the struggle for a couple of years, in a much more moderate manner than in 1994.

Given the seriousness of the issue, the results of this struggle were good.

1. It raised awareness throughout the country on the issue of land rights of the Dalits, which had been forgotten even by the left parties. Many books have been written on this subject, and manuals on how to retrieve these lands have been published.

2. The struggle has given a new issue and a new agenda for the Dalit outfits throughout the country to raise their voice and demand their rights. It has given a new platform to many NGOs and Dalit social and political organizations to come together and organize collective programmes.

3. All the political parties in Tamil Nadu announced, in the last two assembly election manifestos, that the Dalits will be given their due land rights.

4. The DMK Government in Tamil Nadu, made a policy decision to distribute 2 acres of land to all landless Dalits in the State. They honoured this policy partially and distributed lands in some districts to a few thousand families.

5. Individual Dalit families, who had lost their DC lands to usurpers from other castes, were able to reclaim and get their lands back in a few hundred cases, especially in Kancheepuram, Dharmapuri, Vellore and Thiruvannamalai Districts.

To this extent, the struggle has been a massive success, though much more is left to be achieved.

Land Rights are a Livelihood Issue, a Health Issue

It is not my intention here to give all the details of this protracted struggle, which lasted more than a year. This has been published elsewhere. I only want to write how the lives of my patients affected me. How could I isolate health and health care from the living realities of people? Without their purchasing capacity, of what benefit are the hospitals and doctors to the poor?

The Ministry of Health and Family Welfare admits that

> Curative services favour the non-poor: for every Re.1 spent on the poorest 20% population, Rs.3 is spent on the richest quintile... hospitalized Indians spend on an average 58% of their total annual expenditure. Over 40% of hospitalized Indians borrow heavily or sell assets to cover expenses. Over 25% of hospitalized Indians fall

below poverty line because of hospital expenses.[2]

This is the story of our people. The government has introduced some 'band-aid' programmes, like the Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA). This Act aims at enhancing the livelihood security of people in rural areas, by guaranteeing hundred days of wage-employment in a financial year to a rural household, whose adult members volunteer to do unskilled manual work. As a temporary measure for poverty alleviation, no one denies the merit of this programme. These programmes attest to the fact that there are more than 300 million destitute people in our country. The country is not able to give them a decent living. The industrialists and bureaucrats are crying foul over the money wasted on the poor!

On the other hand, look at the story of Devendrappa. He was a landless agricultural labourer from Kaligi village of Chitrapur *taluk* of Gulbarga District and worked under the MNREGA scheme. The Gram Panchayat owed him Rs.12,500 for the work he did for the year 2010-2011. For almost a year, he walked daily to the Gram Panchayat office to claim his due, but he did not succeed. He did the inevitable. On 7 January 2012, the village festival day, he committed suicide. "None of the 600 MNREGA workers in Kaligi have been paid their wages for 2010-11"(*The Hindu,* 28.2.2012). The corrupt officials do not hesitate to usurp the hard earned money even of the destitute. The programme has certainly done some good to people of certain states in the country. But will MNREGA provide permanent livelihood to the people?

Now the government is keen on passing the food security bill. Again, it is a positive step forward. Pope Benedict XVI voices the concern of the Church, regarding food security and recognizes it as one of the rights of all human beings.

The right to food, like the right to water has an important

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2 "Mission Document, National Rural Health Mission", op.cit.

place within the pursuit of other rights, beginning with the fundamental right to life. It is therefore necessary to cultivate a public conscience that considers food and access to water as universal rights of all human beings without distinction and discrimination[3].

The important question is: without right to ownership of land water, forests and other natural resources, how do we provide permanent livelihood to our people? How long will we dole out food materials in the name of food security?

To guarantee the right to food for all, it needs to be ensured that water, land and forests are not diverted from food production and to safeguard people's control over these resources. The government has to make a commitment that nobody goes hungry in this country. Further, food security must be understood to mean 'nutritional' security and not just access to cheap food grains.[4]

Unless there is justice in land and water distribution, food production and food distribution, hunger and chronic starvation will be the lot of the poor.

Health is a social, economic and political issue and above all a fundamental human right. Inequality, poverty, exploitation, violence and injustice are at the door of ill-health and the deaths of poor and marginalized people.

Preamble, The Global People's Charter for Health.

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[3] Pope Benedict XVI,. *Caritas In Veritate.* Trivandrum: Carmel International Publishing House, 2009.No.27.

[4] John Chathanatt and Jaya Peter ,ed., *Silent Waves , Contribution of the Catholic Church to Nation Building* , Bangalore : Claretian Publications, 2012, p.86.

10. Moving On

Open your mouth for the mute, for the rights of all who are destitute. Open your mouth, judge righteously; defend the rights of the poor and needy. (Proverbs 31: 8-9)

"I need to move away. I cannot create dependency. The health workers have the knowledge that they need to carry on their work in the villages. They can and should do without me." As I was mulling over these thoughts, one of the health workers came with a request. "Sister, we know how to take care of the health of the people in our villages, but there is a problem which we cannot solve. There are persons in our villages who cannot walk, cannot see, cannot hear and some of them behave abnormally and are violent (her term for persons with intellectual disability). We can do nothing for them. They are either locked up in their homes or roam about the villages. Please do something for them."

I was not prepared for this. I am a doctor and I have no knowledge of training and helping persons with disabilities. The health worker is expecting a solution for all disabilities. It is impossible, I thought. I wanted to forget the whole business. During the monthly meetings of the health workers, this problem, of persons with disabilities cropped up again and again. The parents and relatives of persons with disabilities took up the chorus. I was helpless. I had neither the knowledge nor the resources.

Nevertheless, people were suffering from disabilities and how could I back out?

A Disturbing Reality

It was really disturbing news that, in this information age, the educated and the elite could be so ignorant and insensitive as to de-board, from a passenger aircraft, a spastic person, who had already completed all the air-travel formalities, and had boarded the plane. This untoward incident took place on 19 February 2012. If this could happen to Jeeja Ghosh, who is the Head of Advocacy and Disability Studies at the Indian Institute of Cerebral Palsy in Kolkata, you can imagine the plight of ordinary persons with disabilities. No wonder it is said, that having a disability places you in the world's largest minority group. As an educated person, Jeeja Ghosh had the responsibility of educating the public.

So she wrote in *The Hindu* on 27 February 2012:

> This is yet another incident that shows lack of awareness and a humane touch even among the so-called elite and educated people of the society... There is an urgent need to educate people about the rights of the disabled.

Still more disturbing was the response of The Bureau of Civil Aviation Security. As reported in the papers, the Bureau seems to have said, that there is a high probability of differently abled persons carrying weapons, explosives and other dangerous materials with them. Naturally, the Disabled Rights Group described the regulation as "disability insensitive and outright insult and violations of the human rights of persons with disability."

According to The World Health Organization, "A disability is any restriction or lack, (resulting from an impairment) of ability to perform an activity in the manner, or within the range considered normal for a human being". This definition *per se* gives us a

glimpse of what disability means to a person. The concept of disability varies according to the circumstances and situations of the persons with disabilities. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993, explained that "people may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness". They further clarified that, "A handicap is considered a loss or limitation of opportunities to take part in community life on an equal level with others".[1]

In recent times, there is a change from the concept of individual pathology to social responsibility, for the disabilities suffered by people. This concept was reinforced by The UN Convention on the Rights of Persons with Disabilities (2005). "Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and, thus, excludes them from mainstream activities". Therefore, like racism or sexism, disability is described as a consequence of discrimination and disregard for the unique circumstances of people with disabilities.[2] According to The UN Development Program (UNDP), 80% of persons with disabilities live in developing countries. As the population ages, this figure is expected to increase. The World Bank estimates that 20% of the world's poorest people have some kind of disability, and tend to be regarded in their own communities as the most disadvantaged. Statistics show a steady increase in these numbers.[3]

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1 Anuradha Mohit, Meera Pillai & Pratiti Rungta, *Rights of the Disabled*, [book on-line] New Delhi :National Human Rights Commission, 2006, p.11

2 ibid.

3 World Facts and Statistics on Disabilities and Disability Issues (http://www.*disabled-world.com/disability/statistics*)

Double Disadvantage

The National Human Rights Commission, in its book titled, *Rights of the Disabled*, reiterates the fact of intrinsic connection between poverty and disability. When people are poor, they are likely to suffer from malnutrition, which contributes to disability, especially when pregnant and nursing mothers and young children are involved. Further, they are more likely to live in squalid and unhealthy environments and be employed in hazardous jobs, which expose them to greater possibilities of disability. Children are likely to be raised in less stimulating environments at home. Poverty can also increase stress levels of parents, which, in turn, may lead to harsh, abusive or violent behavior, which may directly affect children physically, or contribute to dysfunctional social and emotional development. Disability, in turn, accentuates poverty. In the absence of adequate societal support and government services, the family's resources are stretched, to provide additional supports to a member with a disability. People with disabilities are also very vulnerable to poverty, if they are not already poor, since disability often results in loss of income, and demands additional expenditure. The extra costs directly related to disability, include expenses on medical treatment, purchase and maintenance of special devices, and travelling to access rehabilitation and medical facilities. A survey of people with disabilities in India found, that the direct cost of treatment and equipment varied from three days' to two years' income, with a mean of two months.[4] The UN reports also corroborate this fact, stating that "Causes of disability are often directly related to poverty: malnutrition causes 20% of disabilities, accidents/ trauma and war 16%, infectious diseases 11%, non-infectious diseases 20%, others, including ageing, 13% ."

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[4] Anuradha Mohit, op. cit., p. 31-32.

Waking up to the Situation

There was no regulatory or promotional authority of rehabilitation services in India, until The Rehabilitation Council of India (RCI) was set up as a registered society in 1986. It became a Statutory Body only in 1992. In 1993, for the first time, a National Policy for Persons with Disabilities was formulated. It stated that "The Constitution of India ensures equality, freedom, justice and dignity of all individuals and implicitly mandates an inclusive society for all, including persons with disabilities. In recent years, there have been vast and positive changes in the perception of the society towards persons with disabilities. It has been realized that a majority of persons, with disabilities, can lead a better quality of life, if they have equal opportunities and effective access to rehabilitation measures."

The National Policy statement of this document summarizes what the document wants to convey: "The National Policy recognizes that Persons with Disabilities, are a valuable human resource for the country and seeks to create an environment, that provides them with equal opportunities, protection of their rights and full participation in society."[5] The National Policy was followed by the passing of 'The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) ACT, 1995'. This Act is now undergoing modification, in consultation with a wide range of stakeholders, so as to harmonize it with The UN Convention on the Rights of Persons with Disabilities. With NGOs forming an advocacy group in favour of the persons with disabilities and pressing for their rights, the Ministry of Social Justice and Empowerment gradually set up a Disability Bureau, in almost all the states.

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[5] *National Policy for Persons with Disabilities.*New Delhi: No.3-1/1993 DD. III, Ministry of Social Justice and Empowerment, Government of India, 2006. p .6.

India conducted the 58th round of the National Sample Survey (NSS) in 2002, and the results were compiled and published in 2003. This included the statistics of Persons with Disabilities. The report contained, for the first time, information on persons with intellectual disability together with information on persons with physical disabilities. Until 2002, persons with intellectual disability did not exist in the government census and statistics. The term 'intellectual disability' is gradually replacing the earlier terms for this condition such as mentally retarded, mentally handicapped and mentally challenged. According to the survey, persons with disabilities constituted about 2% of the total population in our country. Among the different types of disabilities, the prevalence of locomotor disability was highest in the country – it was 1,046 in the rural and 901 in the urban areas per 1,00,000 persons. This was followed by visual disability and hearing disability.

About 55% of the disabled in India are illiterate and, as expected, it was highest among persons with intellectual disability (87%) followed by people with visual disabilities (74 to 77%). The proportion of illiterates among persons with disabilities was about 59% in the rural and 40% in the urban areas. Special Schools for children with intellectual disability hardly existed in the rural areas. The statistics showed that only 45 boys and 9 girls out of 1,000 children, with intellectual disability in the rural areas, went to a special school. The corresponding figures for the urban areas were 141 and 137.

The All-India figure reveals that, among persons with disabilities, about 13% in both rural and urban India were observed to be severely disabled, as they could not function even with aid/ appliances.[6] It is also estimated that India has 3 million children in need of special education. Even though education of children,

[6] "Disabled Persons in India, NSS 58th round, National Sample Survey Organisation," New Delhi: Ministry of Statistics and Programme Implementation, Government of India, 2003.

with disabilities in the country is more than 100 years old, only about 10% of the children are covered by this system. The main reason is that more than 90% of special schools are located in the cities, whereas 90% of children with disabilities live in rural areas.[7]

Take the First Step and the Lord will Walk with You

In order to pacify the health workers, I told them that we would do something for these people. I had not disappointed them so far. I knew what they were saying was true and people needed help. I had seen The National Institute of Physical Medicine and Rehabilitation in Guindy, Chennai. I thought I would send the children suffering from poliomyelitis to this Institute .There they would be supplied with the needed appliances. With the use of these mobility appliances, children would be able to attend schools. Those who needed surgery also would be taken care of. My responsibility would be over. I was happy that I had found some solution to the problems of persons with disabilities. I could do nothing better in the given circumstances.

I told the health workers to bring a limited number of polio affected children and I would give them the ambulance to go to Guindy. They were happy. On their first visit, I accompanied them and introduced the health workers to the doctors and technicians. This became a regular feature. Almost every fortnight, the health workers took a small group of persons with locomotor problems to the Institute in Guindy.

This intervention, though not spectacular, brought cheer to the children. The health workers motivated the parents to send the children to the village school. They went to the schools and requested the heads of the schools to admit these children with

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7 Mani M.N.G. *Inclusive Education in Indian Context* , Coimbatore: Sri Ramakrishna Mission Vidyalaya, 2000

mobility problems. From being immobile and being confined to their homes, callipers and walkers gave them some amount of freedom and mobility. Some were in wheel chairs, some on tricycles; whatever it might be, they wanted to study. Seeing their enthusiasm to study, other children helped and wheeled them to school. After all, education is the right of every child. Orthopaedically handicapped children do not need special schools for their studies. They only need aids and appliances, so that mobility is ensured. I was happy for this move and the health workers were satisfied.

But I was not satisfied. I did not know much about these subjects and I started reading. I needed books and the books were costly. I wrote to The World Health Organization, Geneva, and was happy when I received the parcel of books from them free of charge. These books on disabilities came in very handy. They provided all the information I needed. I prepared a simple format for survey of persons with disabilities in villages. The health workers were trained in methods of taking the survey. They painstakingly went from house to house, and gathered the required information. I went to the villages and did a random checking of the findings of the health workers. One such visit took us to Malaivayyavoor village.

Out of the Mouths of Babes

Even in 1992, Malaivayyavoor village was an isolated, remote village with no roads or transport facilities. We crossed paddy fields, upper caste area and finally reached the Dalit colony. These simple, affectionate people were excited when they saw us coming to their village. The condition of the village was very pathetic. In addition to poverty and lack of employment, the families were burdened with children, who suffered from various types of disabilities. However, they spoke about one particular boy named Balaraman, and requested us to do something for

him. The child was about 7 years of age and did not have the lower limbs. Instead, he had only two small stumps. He could only squat and drag himself on his buttocks. He could not attend school. Even the *balwadi* teacher did not allow him inside.

Like other children with locomotor problems, I decided to send Balaraman to The National Institute of Physical Medicine and Rehabilitation. On that particular day, I accompanied the children to The National Institute, only because, neither Balaraman's parents nor any of his relatives could accompany him. They were very poor. His father was sickly and could not work; his mother worked as a daily labourer to feed the family. She had six children. On our way back from the Institute, we dropped the children in their respective villages. When we reached Balaraman's village, he simply refused to get down from the vehicle and clung to us. He wanted to come with us to our centre. I wondered what I was going to do with him.

Balaraman stayed in a room adjacent to the convent, which was used as the tailoring class. During the day, he dragged himself to the health centre and spent his time there, speaking to the people who came for treatment. I found him very intelligent and he was eager to study. I asked our staff to teach him the alphabet and numbers during their free time. It was only the month of January. By June, I hoped to find a school for him. Gradually, he started talking to us about his family and the village. "My mother works very hard, yet she could not buy clothes for us even for *pongal*", he said. He was sad. One day, he surprised me with his request that I do something for other children of his village, who suffered from different types of disabilities. "Sister, you have done this good deed for me. In my village, there are children who cannot see, who cannot hear and children who cannot behave properly. Please do something for them." I looked at him in disbelief. A severely handicapped, seven year old boy, born without lower limbs, was capable of feeling compassion for others!

I had thought that it was not possible for me to do anything about the blind, the deaf, the spastic and the intellectually challenged. I had tried to forget about it, but now the words of this little child stung my conscience. Why had I not trusted the Lord? Is there anything impossible for him? Once we show good will to work for the people who suffer, the Lord does not allow us to stop half way. "Unless you become a little child, you cannot enter the kingdom of God", was the lesson I learnt that day.

A Train Journey

It was 30 June 1992. I was on a train journey from Chennai to Bangalore to attend the General Advisory Council Meeting of the Congregation. Working in the health centre, with its 24x7 availability, was exhausting. Thus, any journey that I was obliged to undertake, even if it be a short one, was welcome. It meant a peaceful time for body and mind, as there would be no emergency calls and the consequent stress and tension. In the quietness of my mind, dreams started taking shape. The words of that child resounded in my ears again and again: "Please do something..."

There was fear and anxiety in my heart. Was I expected to undertake this new work? Was it not presumptuous to start a work without personnel, finance and other resources? Sister Preethika had come to the community on a transfer. Perhaps she could be trained for rehabilitation services. We had our special school in Mangalore and she could be sent there for a few months for the training. I needed the approval from higher authorities. All of them would be in Bangalore for the meeting. So I could meet them and speak to them personally.

My thoughts went to Balaraman and other children with disabilities, whom I had seen in the villages. I hoped that I would be able to do something for these children and improve the quality of their lives. There were children and adults with

different types of disabilities. Which of the groups would be my priority? This was the next question in my mind. Though there was no money available for the purpose, I wanted to do something, at least for the children. I had seen the special schools for the visually and hearing impaired children in Chennai and even in Chengalpattu town, but there was no special school for the intellectually challenged anywhere close by. These were the most difficult children to train and to care for. However, my congregation had the tradition of training these children in St. Agnes Special School, Mangalore.

By the time I went over these possibilities in my mind, I had reached Bangalore. "You have no building," said the provincial superior of the southern province. "I have an old leaky shed and that will do", I said confidently. "And funds?" was the next question. "God will provide," I answered, with the same confidence. There were no more questions. "Why send Sister Preethika only for three months to St. Agnes Special School? We are starting the course for Teacher Training for the special educators," the provincial superior of Karnataka enlightened me. "You can send her for the course." My journey to Bangalore had ended well. I was embarking on another journey, to an unknown future.

I slept and I dreamed that life is all joy,
I woke and I saw that life is all service.
I served and I saw that service is joy.

Mother Teresa

11. A Dawn of Hope

People came out to see what had happened, and when they came to Jesus, they found the man from whom the demons had gone, sitting at the feet of Jesus, clothed and in his right mind. (Luke 8:35)

It was an unusual sight for the people of Palliagaram village to see children of ten to twelve years being carried by their parents; some were howling and screaming; still others were outright violent. It was 5 July 1993, the inaugural day of 'Udayam Rehabilitation Centre'. Twenty-five children, with intellectual disability, and their parents, the health workers and five sisters gathered in a rickety old cow shed, modified for the purpose. There were no VIPs, no ribbon cutting and no inaugural speeches.

Until recently, there were no comprehensive national statistical data available, concerning persons with intellectual disability. However, there were a few limited surveys to ascertain the extent of this disability. Based on these surveys, it is estimated that 2-3% of the population suffer from intellectual disability.[1] It means about 3 million people in India are affected by this disability. According to the 2001 census, intellectual disability is 10% of all disabilities. Intellectual disability is defined as a condition of arrested or incomplete development of the mind of persons, which is especially characterized by subnormality of intelligence.

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[1] R.S. Pandey and Lal Advani, *Perspectives in Disability and Rehabilitation*, New Delhi :Vikas Publishing House Pvt. .Ltd, ,1995, p. 28.

This results in limitation of two or more of the adaptive skill areas, such as, communication, self care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Intellectual disability, unlike mental illness, is not a disease but a disability and, hence, there is no cure for the condition. With appropriate support and teaching, most individuals can learn to do many things.

The causes of intellectual disability are many. They vary from chromosomal abnormalities, such as, Down's syndrome, to severe malnutrition and infections in the mother during pregnancy. Intake of drugs and chemicals during pregnancy as well as complications of pregnancy are other causes of this disability in the child. After birth, it is mostly brain fevers and other infections, suffered by the child that cause the problem. In a certain percentage of cases, no specific cause may be found. In about 84% of the cases, children suffer intellectual disability from their birth.

The United Nations Convention on the Rights of the Child defines the basic rights of children, and it covers the multiple needs and issues of children. India endorsed 'The Rights of the Child' Charter in December 1992. Article 23 of the Convention on the Rights of the Child states: Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

1. Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

2. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.[2]

As citizens of a civilized society, it is the right of people with intellectual disability to lead their lives with respect and dignity. It is possible to achieve this goal by bringing about positive changes in societal awareness, attitudes and beliefs about this condition. It is vital to ensure that the same environmental conditions of everyday life are available to people with intellectual disability as they are for anybody else. It also means providing them with facilities to enable development of their full potential.

A Small Beginning

In May 1993, Sister Preethika returned after her training in special education. Meanwhile, the village health workers had completed the survey; they had done the spade work needed to start the programme. 'Udayam' means dawn, and it was meant to be a 'dawn of hope' for persons with disabilities of Kancheepuram District. There was just one large room with a

[2] Convention on the Rights of the Child. Geneva: Office of the United Nations High Commissioner for Human Rights. 1989. http://www2.ohchr.org/english/law/cre.htm#art23

low, leaky roof and mud plastered floor. This one room served as a classroom, bedroom, dining room, as well as the space needed for physiotherapy and other activities for these special children. Just as one room served all purposes, Sister Preethika was teacher, cleaner, physiotherapist, warden - all rolled into one. On the first day, twenty-five children were brought, but only eight parents were willing to leave their children with the sisters. People did not believe, that these children could be trained to live a better quality of life. According to them, it was all a waste of time. We heaved a sigh of relief. With the limited facilities we had, we could not train and take care of more children with intellectual disability. Initially, every child had to be fed and needed assistance for every personal need. For a few months, all the five sisters of the community helped in feeding and taking care of the children.

The systematic training, hard work, love and dedication of Sister Preethika, her helpers and the other sisters of the community were rewarded beyond our expectations. The improvement in the behavior of the children surprised everyone. The individualized education programme, including behavioral modification therapy, helped the children with violent behavior to calm down and to become aware of their surroundings. Within three months, the children became sociable and were learning the daily living skills. They became an advertisement for the Special School. They could not speak clearly, but visitors could see the transformation effected in these children within a short span of time. Prabhu, a six year old boy, used to wave out happily to the people who came to see the place, and told them that the children were happy at Udayam and that they also could leave their children there without hesitation. He did not use so many words. In fact, he was a child with spasticity and with mobility and speech problems, but people understood what he wanted to communicate.

Very soon, the number of children started increasing. All the

same, it was an uphill task and unremitting labour, requiring immense patience and strength. I had initiated the programme, but my responsibility was at the health centre. I could not help with the caring and training of children. The leaky roof and wet floors tried our patience. The whole place used to be flooded. Snakes and frogs found their way inside. One night, we watched in horror a cobra crawling over the sleeping children. Fortunately, no one moved. God watched over his special children.

How long could we go on in this miserable situation? With no funds or other resources forthcoming, I was not so sure now about the wisdom of having started this Rehabilitation Centre. I felt I was burdening others unduly. Was it worth all this trouble?

A Divine Intervention

I happened to be again in Bangalore, attending the General Chapter of the congregation. It was 4 June 1996. The Chapter was coming to an end. "There is not a drop of water in the well", Sister Preethika telephoned. "We cannot reopen the school and the home for the children on Monday. I shall inform the parents not to bring the children". Drought years were common in the area and, sometimes , drought years followed one after another. People and cattle had to go to far away places in search of water. Such years were 1995, 1996 and 1997.

It was the third year of the existence of Udayam Rehabilitation Centre. The number of children, from eight at its inception, had risen to over forty. The children with intellectual disability and spasticity needed plenty of water for daily washing of clothes, bath, cleaning and other needs. So, I knew that the problem was real. "No, the school will reopen on Monday. Do not tell parents anything," I told Sister Preethika. I had no idea whatsoever, how I was going to solve the problem. The north east monsoon would start, if at all, only in October.

The General Chapter was over and I reached Palliagaram on 8

June. There was no drinking water for the four sisters of the community, and how were we to provide for forty students and the staff? We were faced with an insoluble dilemma.

I requested the sisters to go to the neighbouring farm, and ask them to let us have some water. They had a huge farm with many wells and had plenty of water. A few years earlier, they had provided water for the sisters and the health centre. We were only four sisters then. They knew that now things were different. The sisters returned with a negative answer from the manager of the farm. It was already Sunday, 9 June.

That night I cried out to the Lord in prayer. In starting this Special School and Rehabilitation Centre, I had been facing many problems. Now, this dry well was, as it were, the last straw that would break the camel's back. I begged the Lord, to show me whether it was his will or not, that I continue this work. If he did not provide water for the children the next day, I was going to close down the school. I had enough problems and I could not stand it any more. With this decision, I went to sleep with peace in my heart. True, we had a huge well, but without any ground source of water. It was more like a storage tank. At present, it was completely dry.

But, lo and behold! It started raining that night and rained continuously for three days. The huge well was almost full. The newspapers reported that in the past hundred years, it was only for the third time that Tamil Nadu was experiencing this type of abnormal, out of season rain. We , sisters, knew the cause of the rain and we would never doubt again the plan of God with regard to these, his dear children.

Miracles are not the events of a bygone era. When God wants to accomplish something through human mediation, he will see that the obstacles are overcome and the resources are provided almost out of nothing.

All is Well

As the number of children increased, the one room school and home became impractical. With the help of friends and benefactors, a well planned special school was constructed. Now the children had well ventilated classrooms and activity rooms. A sufficient number of trained teachers were appointed. We were proud of our well equipped physiotherapy section. Occupational therapy and skill training sections were added. Later on, we were also able to construct a residential home for the children.

The special school was a blessing for these children with intellectual disability. After the individual assessment of children, the training started on a priority basis. A file, with all the particulars of the child and his/her assessment and progress, was maintained. The 'daily living skills', such as, toileting, feeding and dressing, were the first priority. Normal children learnt these skills by observation, but, for these children, such skills had to be broken down to smaller components and it took 3-4 months before they learnt to button a shirt, brush their teeth, or comb their hair. Once they mastered these basic skills, teachers went on training them in other motor and sensory skills. Each child was evaluated and helped to progress, according to his or her capacity. Soon, children were learning the alphabet, numbers and money concepts. We had a good team of staff, including special education teachers, physiotherapist, craft teachers and a teacher with a diploma in Vocational Training. Yoga, music, dance and sports formed part of the daily routine.

We wanted the children to take part in competitions viz. sports and cultural programmes on the district and state levels. They could not understand why they had to compete; they waited for one another; they helped those who could not run. However, because of the departmental insistence, we had to train them

for sports competitions. Finally, some of them did win a few trophies. When someone won the prize, everyone rejoiced. The idea of competition was alien to their mentality.

Finally, their spirit of cooperation, not competition, caught up with us, sisters, and with the staff too. For the annual day of the school, we started giving every child a prize for his or her achievement. After all, each one's level of performance was different. All had done their best. This is easy of course in the special schools, where the number of children is small. With recognition of different types of intelligence in human beings, one standard scale of measuring the performance of children, even in regular schools, may not be the ideal. No wonder that the systems of grading, instead of marks in the examination, and 'no-examination' in the schools are becoming popular.

They Love One Another

Udayam had residential facilities. This benefitted children from far-flung villages. Just as in the case of our health centre, here too no one was excluded. Disability was prevalent in all sections of society. However, 90% of children in Udayam were from Dalit families. Dalit parents did not have, either time or facilities to bring children to school daily and to take them back home. All the same, the children need parental love and should not feel abandoned. We made sure that the parents continued to care for their children. "You will be responsible for your children. We will help you to train them," was our message to the parents.

Initially, it was compulsory for the parents to take their children home for every weekend. Later on, it was changed to fortnightly visits. Once the parents understood that they could not abandon these 'troublesome' children to our care, this rule was relaxed. Now, the children are taken home during the stipulated

government holidays. Child-parent relationship was further strengthened by weekly and fortnightly visits from parents and relatives. The sisters and the staff shared their love, time and energy with the children. These children had been isolated, neglected and lonely in their homes. Now, they found a new joy in living.

They learnt to care for and help one another. One day, the sisters brought new toys and other materials, that were needed for children's play and games. As the packets were being opened, the children with intellectual and hearing disabilities ran to bring the visually impaired children and made them touch and feel the new toys. The sisters did not remember, for a moment, that there were children there who could not see, but the children did not forget. They had observed the method of teaching the children with visual impairment. The children realized, that all of them had some problem or the other. It brought tears to our eyes to see the children with intellectual disability, spasticity and visual and hearing impairment, helping one another and being concerned about one another. Usually, the children with intellectual disability are regarded as useless and good for nothing. We, who lived close to them and observed them, knew that there was a lot of goodness in them. Their spontaneity and concern eased our tensions and anxieties. Very truly, they are 'differently abled' and not disabled children.

Give us an Opportunity

Job training of the children included, among other things, cooking and other household chores. With money concept already learnt, they became confident enough to run a snack shop on the campus. They prepared tea and snacks and sold them to the people who came to the health centre. There were no tea shops anywhere close to the health centre. The patients and relatives were happy

with the snack shop on the campus. Whatever profit was gained from their work, was shared among them and deposited in the bank in their name. This trained them for self-employment in the future. They learnt tailoring and basket making. We sold these items too and the children got their share of money.

Devika, a girl with cerebral palsy, was one of the first children to be admitted into the special school, Udayam, in 1993. She was five years old and could not walk. She had to be carried from place to place, was afraid of strangers and was also physically very weak. She was given physiotherapy exercises regularly. Within two years, she was able to walk with the support of a walker. The Special School also helped her to acquire the basic academic skills of reading and writing. By the end of her fifth year in Udayam, she was able to walk without support. She was trained in tailoring and garment making. With all these improvements, her mother was happy to have her back home.

Sudha was another five year old girl with intellectual disability admitted in 1993. She had severe drooling, due to which the skin on her chest and neck had peeled off. She was unwilling to put on clothes, could not swallow and could not speak. She was totally dependent on others for all her basic needs. After assessment, a systematic programme was started for training her. Now, she is not only independent in looking after herself, but also able to look after other children. She learnt tailoring and has become an expert in this. She now stitches uniforms for Udayam Special School. "Her work is very neat, she does not need any help in stitching the uniforms and she earns a salary", says Sister Preethika. She feels respected by others ,and her parents and siblings are happy with her. [3] She earns her salary as a staff member of Udayam.

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3 *New Frontiers*, op. cit.,p.363.

Prabhu, from Edamuchi village, was a six year old boy when he was brought to Udayam. As he could not walk, he was carried by his parents. Neither could he talk. Again, after the assessment, physiotherapy and speech training and other skills needed were started. He learnt to walk, even though he wobbled a little. He learnt to read and write the alphabet and simple sentences. He learnt to make wire baskets. Then he went home; he continued to make baskets and sold them and earned money. His pleasant nature helped him to make friends with neighbours and with his peer group in the village. When the village set up a library, he was given charge of maintaining it, so he earns a monthly salary. He has a cell phone and called Sister Preethika to give her this good news.

I cannot forget Manikandan, a boy with a severe degree of spasticity. He was already nine years old when he was brought to Udayam. His upper and lower limbs were twisted. He could not hear and could not speak. He could communicate only with his eyes. Initially, he was apprehensive of strangers. Very soon he realized that all were interested in him. The physiotherapist tried to straighten his limbs. The limbs, already set in a position, could not be stretched easily. It was very painful. However, Manikandan fought back his tears and tried to smile. He knew the physiotherapist was doing everything possible for his good. He did not want to pain anyone. His body was distorted and disfigured, but his mind was gentle and kind. This was a lesson for us. The children with intellectual disability and hearing impairment wheeled him around. If any one of us was absent from Udayam for sometime, it was Manikandan who would express his joy at our return by waving his uncontrollable hands and with his exuberant smile.

These are just a few examples of children, with intellectual disability and spasticity, who were trained in Udayam. Some

of the boys are gainfully employed in the factories, that have sprung up around Palliagaram. Still others, both boys and girls, are self-employed. Just like other people in their villages, they work in the fields, or are engaged in cattle rearing and household work. The staff from Udayam continues to follow up those who are employed, both outside and in their homes.

Everything is not Cosy

As The National Sample Survey indicated, 13% of all persons with disabilities suffer a severe degree of handicap. Udayam did not refuse to care for these children. They were admitted and given special care. Of course, the special educators, knew different techniques to be used for stimulating, whatever residual sensory and motor functions these children might possess. These children needed a person all the time with them for their toilet needs, cleaning, feeding and so on. For the poor families this becomes a problem. They need to work for their daily living, and they cannot afford to employ anyone else for the purpose of looking after these children. The parents were very grateful for this service rendered by Udayam.

We had a high proportion of children with cerebral palsy and that too, of a severe degree. Cerebral Palsy (CP) is a term used to describe a group of chronic conditions affecting body movements and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during foetal development or infancy. It can occur before, during or shortly following birth. A severe form of cerebral palsy could involve significant muscle problems in all four limbs, and may also cause intellectual disability, seizures, and difficulties with vision, speech, and hearing. We had quite a number of children with these problems. Thus, the teachers had to deal with children who suffered from multiple disabilities. This was

not easy. It was even difficult to get helpers to look after these children.

Lakshmi, a seven year old girl, was tied up in her house because the parents had to go for their daily work. She was blind. She was not trained to take care of her personal needs. When she was brought to Udayam, and when the staff started the training, they realized that she was also a child with intellectual disability. It was a big challenge. With patience and perseverance, the staff continued training her. In fact, we had 3-4 children with a combination of blindness and intellectual disability. We found that this combination was a greater challenge than other multiple disabilities.

We had residential facilities which were a blessing for parents who had children with severe and multiple disabilities. With children, who suffered from congenital abnormalities and uncontrollable seizures, episodes of sickness and even the possibility of death were always there. All these difficulties and challenges did not deter us from caring for these children. The details of their medical history were recorded and we saw to it that they received proper and regular medication. Our health centre and Chengalpattu Medical College were always there to help Udayam in case of any emergency. The parents were kept informed about the medical conditions of their children and they were expected to come and be with them in the hospital, in case the children were hospitalized. We had to face the tragedy and stress and tension of two children dying, fortunately both in the hospital.

Intellectual disability, and its accompanying complications are the most difficult disability to deal with. Knowing these facts, I had taken up the challenge. Fortunately, the staff of Udayam was committed to the cause. They faced the tensions and difficulties

inherent in this work in a spirit of love and compassion. They will surely be blessed by God for their unstinting services.

I am happy that Udayam has, in a small measure, contributed to the care and training of children with intellectual disability. It was not their fault that they were born with, or developed such disabilities. They had all the right to receive the care and education that they needed to lead a dignified life. We were able to prove that, by providing the right kind of support and services, it was possible to ensure, that those with intellectual disability can lead healthy and relatively independent lives.

Christ has no body now, but yours.
No hands, no feet on earth, but yours.
Yours are the eyes through which
Christ looks with compassion into the world.
Yours are the feet with which Christ walks to
do good. Yours are the hands with which Christ
blesses the world.

St. Teresa of Avila

12. We Cannot Be Left Out

Great crowds came to him, bringing with them the lame, the maimed, the blind, the mute and many others. They put them at his feet, and he cured them. (Matthew 15:30)

Balaraman was already in school. A few children with poliomyelitis were using callipers and shoes and they were going to their own village schools. They were fortunate to attend regular government schools. "What about our children?", asked the parents of visually and hearing impaired children. The statistics tell us that after the locomotor disability, the visual and hearing disabilities are the next highest in the order of prevalence. "We cannot send our little ones so far away to the city institutions. Please do not leave us out. Help our kids too," they pleaded.

They certainly deserved help. They were poor, and they also had the additional burden, of caring for their children with disabilities. They were right in their demand. I was happy that they loved and cared for these children with problems. However, for the training to be effective, it had to be initiated at an early age, at least at the age of two or three. It was not practical to send the little ones, with vision and hearing problems to the existing special schools, which were far away in the city. This was again a new situation, and we had to evolve a strategy for educating these little children. We decided to admit these children, with hearing and visual impairments in Udayam Rehabilitation Centre.

Thus, within six months of inception of Udayam Rehabilitation Centre, it housed and trained children with intellectual disability, spastic children, as well as children, with hearing and visual impairments. Our resources were limited, and I had no intention of making our centre a large complex with different specialties. While making our services available to people in need, we needed to be practical. The services had to be comprehensive, integrated and inclusive at the same time.

Fortunately, I had information that the Holy Cross College, Trichy was training the special education teachers, with a view to providing integrated education. They were trained to teach both the hearing and visually impaired children. Their curriculum prepared them to be resource teachers for integrated education. I lost no time and appointed three of these teachers as staff of Udayam Rehabilitation Centre. The children, who were as young as two year old, were brought from nearby villages to the centre. Usually it was the grandparents who brought these little ones in the morning, and also took them home in the evening. Children from far away villages had to be admitted in the residential home, and so they were brought at the age of four or five. The teachers started training children with hearing impairment, in speech skills, and visually impaired, in mobility and tactile methods of identifying objects, and finally the Braille method of reading. Once the children mastered the basic skills, we could integrate them into regular schools.

The Blind will See, the Deaf will Hear

Here was the hurdle. No regular school was willing to admit these children in their schools. The National Policy on Education (NPE-1986) devoted a full chapter on 'Education of the Handicapped'. It stated that "Government is firmly committed to providing education for all, the priority areas being free and compulsory elementary education, covering children with special needs,

eradication of illiteracy, education for women's equality, and special focus on the education of SCs/STs and Minorities." The National Policy on Education gave a boost to the centrally sponsored scheme of Integrated Education for the Disabled Children (IEDC) initiated in 1974. The idea was to integrate children with disabilities into the main stream of education.

Unfortunately, due to various reasons, the programme did not take off as expected. I went to the Chief Educational Officer of Kancheepuram District. He had not heard about such a programme, and had not received any orders from the State authorities. Naturally the schools refused to admit children with disabilities, in spite of our assurance, that we would be supporting them with the expertise needed. I am talking about the year 1993. Now, with the universalization of elementary education and 'Education for All' (*Sarva Shiksha Abhiyan*), becoming the government policy from 2000-2001, the government schools and private schools to a lesser extent, are willingly admitting children with special needs.

One day in the year 1993, remembering that every challenge is an opportunity, I went to The State Directorate of Education, Chennai. What a surprise it was! A person appointed as the Director of Integrated Education had his office there and was getting his regular salary. "What can I do? No one is interested in this project," he complained. I sympathized with him and told him, that I was ready to help him in implementing the project. I would organize a motivational seminar for the heads of the government schools. He needed to come only as a resource person. I requested him to make copies of the Government Order (G.O.) available to all the participants. He was wondering how I was going to conduct the seminar for the government teachers.

As a doctor, I was well known and respected in the area. The heads of the government primary schools agreed to come for the seminar on integrated education. One of the schools offered

the place to conduct the seminar. The Director in Chennai was astonished that we had already fixed the date for the seminar. The Director gave the participants a copy of the G.O. on Integrated Education. Two such seminars were conducted, and more than sixty heads of the government primary schools attended these seminars.

Still, all the schools were not willing to take on this additional responsibility of integrating the children with disabilities in regular schools. After much persuasion and cajoling, some of the schools agreed to admit the visually and hearing impaired children in their schools. They had to admit children only from the same village where the school was. It was not only the teachers who created difficulties, but also some of the parents as well. They had heard about the special schools. They thought that it was presumptuous, on our part that we were attempting to educate their children in the regular village schools.

Fortunately, the resource teachers were resilient. Many were the hurdles that they had to face. They went in turn to different schools, for one or two hours per day, so that they could coach the visually and hearing impaired children, and impart the special skills they required. The schools would not give them any place, for taking up these special sessions. They sat under the trees or, wherever they could find some place. They also interacted with other children and the teachers. It took many months of hard work, before their efforts were recognized and rewarded. The teachers and the parents became aware that the visually impaired and hearing impaired children were intelligent, and that they could be educated in regular schools. Only the teachers needed to be trained. The other students befriended the 'special children'. It was a joy to see these children playing with their class mates in the regular schools.

In 1994-95, about twenty students, with visual and hearing impairment were studying in ten different schools. It meant that

these children lived in their own homes with their parents and siblings. The resource teachers divided their time among these different schools. They kept in contact with the teachers in the schools and the parents in their homes, so that the teachers and parents learnt to communicate with these children and to love and care for them. This move really changed the life of the children with disabilities. Now these children, with visual and hearing impairment could go to schools in their own villages, and could play and communicate with children of the same age. They not only received an integrated education, but were also integrated into the social life of the village community. They were loved and cared for by their families and friends. People no longer looked upon them as abnormal.

Inclusive Education is a progressive step forward towards achieving 'Education for All'. Inclusive education is an approach, that looks into, how to transform education systems and other learning environments, in order to respond to the diversity of learners. It aims towards enabling teachers and learners, both to feel comfortable with diversity, and to see it as a challenge and enrichment of the learning environment, rather than as a problem. When we started integrated education in 1993-94, there was not much talk about inclusive education. Nonetheless, with minimal support from the resource teachers, children with disabilities were fully at home in the regular schools, in their families and in their village community.

The Lame will Walk

In the initial stages of the rehabilitation services, we had helped a few children with callipers and shoes so that the polio affected children could go to the local schools. However, that was only a limited service. We were happy when a NGO, 'Mobility India', Bangalore, offered to collaborate with us. They were ready to help us in a big way to be of service to the village people. After

all, locomotor problem was at the top of the disability list, and we were happy with this partnership.

The staff from Mobility India, trained our Community Based Rehabilitation (CBR) workers in conducting a detailed survey of locomotor disabilities. About two hundred villages in Uthiramerur, Maduranthakam and Acharappakkam Community Development Blocks of Kancheepuram District were surveyed. Three camps were conducted for the affected people. This ensured a proper diagnosis of the disability, the people suffered from, and they could also assess the type of aids and appliances the individuals needed.

A Workshop on the Campus

With a large number of people needing callipers and shoes, as well as other aids and appliances it was not practical to get the supplies from Bangalore. So it was suggested that we have our own workshop, for production of callipers and shoes. At this stage, we could not disappoint the people. The garage was turned into a workshop. Initially Mobility India sent their technicians to the workshop. 95% of our staff in the special school was from our own locality. We wanted our own technicians for the workshop too. Two persons of our choice were sent for the training. They completed a year's training in Bangalore and returned to Udayam.

From then onwards, the workshop in Palliagaram supplied callipers and shoes, as well as other aids and appliances, needed for the people with locomotor problems. The staff from Mobility India came on and off to check on the quality of production, and for further need assessment. Artificial limbs could not be produced in our workshop. Mobility India supplied them and they were of very good quality. People from all over the neighbouring villages brought persons, both children and adults who needed these appliances. The children were very happy to go to schools with

other children of their village. With this newly found freedom of movement, many of the adults could find some job or the other and could earn their living. Earlier, they were confined to their homes and were considered as burdens and liabilities by their family members.

Love Unto Death – the Story of Chandra

Chandra was an amputee from Kodithandalam village. She underwent above knee amputation for osteosarcoma, a type of bone cancer. She was a Dalit woman and her family was very poor. She had four girls, and the husband did not have any work. He had been an unskilled worker in a small factory. When the factory was closed, the workers were sent away without any compensation. Now that she was sick, and her leg amputated, she could no longer work in the fields like other women of her village and earn a living. Her daughters were in school. She loved her daughters and she wanted to educate all of them. Now with her illness, and the husband losing his job, her dreams were falling apart. With starvation staring in the face, she was distraught and anxious.

It was at this time, that she heard about Udayam Rehabilitation Centre and the camps, that we were conducting. She attended one of those camps in her own village. Finally, she was brought to the centre to be fitted with the artificial leg. Her spirit revived. Chandra was a woman of strong caliber and will power. She requested us to give her some job at our centre. She was illiterate. She was ready for any work, she said. We could give her only the job of cleaning the school and helping children with their personal needs. All this would mean that she would have to be on her feet all the time. Moreover with four girls at home, she would have to travel every day to and from our centre. She would, also need to get into crowded buses and then walk another two kilometres from the bus stop to her house. As she stood in front of me with

her request, I was thinking how she would manage the situation. She understood my hesitation. "I will not disappoint you. Please do not refuse me." She said.

If I do not give her a job, then who will? So she was on our staff for nine years. With the artificial limb fitted, she swept and cleaned the school, and took care of the personal needs of children with intellectual disability and spasticity. She came on time to the school and we did not have any reason to complain about her work. She had a smile for everyone, and she was gentle towards the children. She never complained of her pains and tiredness. I could see the determination on her face. She wanted to keep the job at all cost, so that her family could live a decent life.

During those nine years, she managed to educate her daughters. All of them completed, not only schooling, but also did some technical or professional diploma courses. At the end of the nine years, there was recurrence of the cancer and she was too sick to work. Even in her semiconscious state, she would call out the names of the sisters at Udayam. Her husband and the daughters looked after her until her death. Her husband was reinstated in his job just before Chandra's death and she was very happy. Chandra lived a sacrificial life for the sake of her family. All of us at Udayam were happy, that we were able to help Chandra to fulfill her dream of caring for her daughters, and of educating them.

The story of Chandra illustrates the struggles of persons with disabilities, who are poor and of the labouring class. With Udayam expanding its services to the needs of people with different disabilities, it really proved to be 'Udayam', a dawn of hope for all persons with disabilities. Like Chandra, many adults were able to earn a living and be independent. They were also a support to their families. Moreover, Udayam Rehabilitation Centre can be proud, that children who were deaf, blind and lame have finished their schooling, and are employed in different capacities.

Balaraman, the boy without lower limbs completed his B.com and computer studies and is working as a designer in a studio in Chengalpattu. His tenacious nature helps him to travel daily, using the public transport from Malaivayyavoor village to Chengalpattu, a distance of 25 kms. His dream is to secure an automated two wheeler from the District Rehabilitation Centre.

Arumugham, a visually handicapped boy, who was one of those integrated into regular schools, completed his B.A. and worked for some years in Udayam as assistant physiotherapist. Now he is planning to do his postgraduate studies in English literature. These are just a few examples of achievements, of children with disabilities from remote villages. All of them look upon Udayam as their mother, and they keep in touch with the sisters and staff of the centre.

Partnership for People

I was confident in my field of expertise of health and health care. I did not need any one to be a partner in our health programme, except when we had to take on the socio-political issues. However, the field of disability was a little different. I did not have any specialized knowledge in this area. I am truly convinced that the Lord was directing all the activities of the Rehabilitation Centre. How else could we explain the number of national level Institutions and NGOs who contacted us, and were ready to collaborate with us?

Prof. Jayanthi Narayan, the Head of The Department of Special Education of National Institute for the Mentally Handicapped Hyderabad (NIMH)was the first person to visit us. It was in the year 1993. We were still in that old leaky, dilapidated shed. There were hardly any facilities. That was not a problem for her either. She was impressed by the commitment of the staff and progress of the children. At that time, Sister Preethika had just a year's

training in special Education. Moreover, she was the only trained person available during that period. Prof. Jayanthi Narayan and her assistant did a complete psychological and behavioural assessment of the children. This helped Sister Preethika to record the individual assessments, and the progress of the children. The professor was seeing a special school in such a remote village for the first time. She wrote an article about 'Udayam' in their newsletter. Later on I was invited to speak to her students, about our experience of teaching mentally handicapped children of rural areas.

Spastic Society of India, Chennai was very happy to train our health workers, and CBR workers in caring for the spastic children. They conducted theory classes at our centre, and then went to the villages to train CBR workers in the actual situation of spastic children. Thus we were able to initiate, very meaningful home based services in the villages. The staff from the Spastic Society continued to come for two years and more, until our staff were confident to deal with the cerebral palsied children. The Spastic Society of Tamil Nadu also visited us, and gave us all the help that they could.

We were surprised to receive a letter from ADD(Action on Disability and Development), India, Bangalore. The letter said that, they were willing to train our CBR workers to organize self-help groups of persons with disabilities. That is what I was just waiting for. We had trained women to be self-reliant, and self-confident. I was not sure whether we could do the same for Persons with Disabilities (PWD). Here was the answer. CBR Workers were trained step by step in the process of organizing the PWD into self-help groups. Self-help groups became the backbone of the CBR Programme. This is a chapter by itself. We have already spoken about Mobility India, Bangalore and their contribution to the rehabilitation programme of Udayam. Then there was Holy Cross College, Trichy, who trained the resource teachers for the Integrated Programme.

Each of these organizations was aware only of their part of collaboration with Udayam. I wanted them to meet one another. They were called for a partner's meeting. They were astonished to know, that there were so many of them who were collaborating with Udayam. Some admired Udayam for organizing such a comprehensive programme, with many different components. Others were wondering how this was possible. They were finding it difficult to carry on just one programme. "I do not think it is a good idea that so many things are started at the same time by the same organization," one of them remarked in good faith. They thought it was impossible and difficult to manage such a large programme. For me, it was a natural outcome of responding to people's needs. There was nothing difficult or burdensome about it.

> The purpose of life is not to be happy
> but to matter, to be productive, to be useful,
> to make some difference that you have lived at all.
>
> *Leo Rosten*

13. We Are Able

What is the kingdom of God like? And to what should I compare it? It is like a mustard seed that someone took and sowed in the garden; it grew and became a tree, and the birds of the air made nest in its branches.

(Luke 13:18-19)

We can; we are able; we need opportunity; We demand our right to live with dignity. Chengalpattu town vibrated with such slogans of Persons with Disabilities on 3 Decemebr 1997, the World Disabled Day. The State governments, as a rule celebrated World Disabled Day with sports, games and cultural programmes, with the help of special schools. "Of what use are these programmes?" asked the adults with disabilities in the villages.

About 1,500 persons with disabilities thronged Chengalpattu town for the rally. The town, famous for many processions and rallies, had never witnessed such an event before. Disabled as they were, most of them walked. The persons with severe disabilities came in vehicles and wheel chairs. The purpose of the rally was, to create awareness in the public, regarding the rights and needs of the persons with disabilities. They had a public meeting and submitted their petitions and demands to the District Rehabilitation Officer.

The prevalence of disabilities in any population is about 2-3%. How many of them would Udayam be able to accommodate,

train and offer rehabilitation services to? The Special School and the residential home could cater, only to a maximum of 100 children at a time. What about those severely handicapped persons in hundreds of surrounding villages? Fortunately, I had the experience of organizing community based health services. I realized, that I would have to adopt the same strategy of community based programme, in the area of disabilities as well. Within a few months of existence of Udayam, Community Based Rehabilitation Programme (CBR) was initiated. It was prophetic perhaps, that 'Udayam' was named not as 'special school', but as 'Rehabilitation Centre', even though the first programme to start, was the special school for the mentally challenged children. Udayam was destined to be an umbrella organization, covering a variety of programmes.

When the concept of CBR was still in its early stages, Udayam already in the year 1993, took the rehabilitation services to the community. A curriculum suited to the local conditions, was planned. The training of Community Based Rehabilitation Workers began in earnest. Just as in the case of health workers, insistence was on practical application of the theory. So we interspersed theory classes with practical field work. After a week of theory classes, they would visit the houses of the persons with disabilities in their villages. This approach gave the CBR workers, the opportunity to familiarize themselves with actual life situations of persons with disabilities. They did not hesitate to tell us the things that they needed to know, and the skills they wanted to acquire. It took six months to ensure a sufficient level of learning. During this time, they were both learners and workers. Later on, they came to the centre every month. They shared their experiences as well as their problems. They were given further inputs. It was an ongoing training programme. Fortnightly visits of the CBR coordinator to the villages, provided the support they required for their effective functioning.

The news of Udayam Rehabilitaiton Centre and CBR programme spread around in no time. That was, when many NGOs showed their eagerness to collaborate with us. A number of resource persons, from various specialties collaborated in training the CBR workers. Each CBR worker was responsible for his/her village, as well as for 6-8 neighbouring villages, depending on the population of the villages and the number of persons with disabilities. With staff from The Spastic Society of India, Mobility India, and ADD(Action on Disability and Development) India, coming regularly for the training of CBR workers, we had a well trained and motivated group of CBR workers. Very soon, the CBR programme spread to four Community Development Blocks of Maduranthagam, Acharappakkam, Uthiramerur and Cheyyur of Kancheepuram District .

Survey and Identification of Persons with Disabilities

Since the programme now extended to many more villages, the CBR Workers conducted a detailed survey of disabilities in the villages. Diseases and disabilities of the elderly were not included in this survey. Udayam in its Annual Report of 1997 recorded the findings of this survey:

The population surveyed	:	1,02,809.
No. of PWD	:	1,968
Percentage of disabilities	:	1.9%

Even though this was a limited survey, this figure, more or less tallied with the National Sample Survey (NSS) of disabilities of 2002, which was 1.8%[1] whereas 2001 census survey showed a higher prevalence of 2.3%. The findings of different surveys may vary, according to the criteria and definitions used for the purpose. Disability specific Data showed that percentage of Movement (locomotor) disabilities was 51%; Visual: 14%;

[1] Disabled Persons in India ,NSS 58 round, op.cit.

Hearing: 15%; Speech: 10% and Intellectual disability: 10%. Our survey confirmed the high percentage of illiteracy among Persons with Disabilities (PWD) in rural areas. 81% of women and 67.6% of men had no opportunity for education. As keeping with the general trend in India[2], this survey confirmed higher percentage of prevalence of disabilities in men, compared to those in women.

On 2 February 1996, the District Collector Sri .P. Ram Mohan Rao inaugurated the newly constructed Udayam Rehabilitation Centre building. In our memorandum to the District Collector, we did not ask any favour for Udayam. We presented, only the result of the survey of the persons with disabilities of Kancheepuram District, giving the details of the number of people suffering from various disabilities. It was an eye- opener for the Collector and for the District Rehabilitation officials who were present there on that day. The Collector ordered the officials concerned, to extend their cooperation, and do all that was needed for the persons with disabilities in the villages. From then onwards, the CBR programme of Udayam had the full support of the District Rehabilitation Centre (DRC).

Services at Their Door Steps

Prevention is better than cure. This adage is very much true, in case of disabilities as well. Early diagnosis and intervention prevents worsening of disabilities. Home based services, and early intervention were part of our CBR programme. The CBR workers visited the families regularly, and consequently, they were able to diagnose the disabilities in infants as early as 3-4 months of age. CBR workers had the support of a physiotherapist and special educators of Udayam. Once a fortnight, the whole team visited the families, who needed the services. They taught

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[2] ibid.

the parents and the relatives the methods of early stimulation and physiotherapy. They also encouraged the people to make walkers and other appliances from bamboo and other locally available materials. The CBR workers followed up the programme with their weekly visits . This early intervention, reduced the severity of disabilities in toddlers and children. Many of them were able to attend schools in their own village. I quote here only one of the many success stories of early intervention by Kumar, the CBR worker.

> I saw Lakshmi in her house a year ago. She was three year old. Her right hand was stiff and bent. Her legs were rigid and crossed (scissors like). She could not sit or stand. She lay whole day on the verandah of their hut. Her grandmother fed her and cleaned her. Her parents had no time for her as they had to earn their living.
>
> I was happy that we were given, a step by step training in handling children with cerebral palsy. I started physiotherapy exercises for Lakshmi. At first her grandmother did not believe, that these exercises would do any good for the child. Week after week, I visited her. Finally, the grandmother agreed to continue the exercises which I taught her. Initially her tight muscles caused Lakshmi great pain and she used to cry. However, she never resisted the therapy and the exercises.
>
> After 10-12 months of continuous therapy, she was able to eat by herself, sit up and stand with support. I am looking forward to the day when she will walk and be independent.

It was not enough that Udayam supported persons with disabilities. These affected people needed the daily support from their families, village communities and the public. Using different methods, such as exhibitions, street plays, skits and

discussions, CBR workers created awareness in villages and schools. Women's groups and youth groups were roped in for creating this awareness. The Decennial Celebration Souvenir of Udayam reported, "The CBR workers conducted a total of 720 sessions of awareness programmes. These sessions covered 15,000 students, 2,800 women, 2,500 youth and 18,000 people in the villages." The methods used varied, according to the level of knowledge of the participants and audience. The methods, included street theatre, followed by discussions in the villages; formal meetings and lectures for the students and staff in the schools, and group discussions, songs and skits for women and youth groups. Youth groups were involved in preparing posters in support of the persons with disabilities and displaying them in the villages. The disparaging remarks, about persons with disabilities, were no longer heard in the villages. Thus CBR workers succeeded in creating a wider support system for persons with disabilities. Our partner organization ADD India was the main support for these programmes.

We Need One Another

People with disabilities, living in the villages, had spent long years in loneliness and isolation. The personal contact with CBR workers, and the resultant interventions helped to create some measure of confidence in them. They were ready to come together, meet one another and discuss and share their problems and needs. These meetings gave them an opportunity for socializing and communication. They gradually realized that it was also a means of asserting their rights. Elango, CBR worker of Pulippakkam village writes,

> I explained to them our objectives and the objectives of the unions to be formed. Initially they were sceptical. Earlier some NGOs had distributed loans without assessing their needs and they were not happy. I told them that

no activity will take place unless they wanted it and the main aim was to foster self-reliance and concern for one another. After some days of discussion , they agreed to try it out.

Now they are happy for the opportunity to come together. They pay the subscription and have saved an amount of Rs. 1,750. The union is named "peacock" and they are really proud of their union and its achievements. They managed to send a polio affected girl for surgery and she is able to walk straight. The union helped a deaf person to start a tea shop so that he could earn a living. They helped members who needed aids and appliances through the DRC scheme. I am indeed happy that 'peacock' is growing. Fortunately I did not give up my effort in the face of initial difficulties and problems.

Within a period of 3-4 years, 61 unions of self-help groups, of persons with disabilities were formed with 700 members on roll. They realized that unity was strength, and they formed a Federation. They took on many problems which they faced in their daily life situations. They discussed the problems and sought solutions .They demanded their rights from the government. World Disabled Day was made use of, to organize rallies and processions to demand their rights, as persons with disabilities . The rallies and processions became an annual feature and they were held in different towns, in order to create a wider awareness among the masses of people.

Right to Marriage and Sex

According to the draft definition published by The World Health Organization, sexuality is a central aspect of being human.

However, there has been a widespread assumption through the centuries, and across cultures that people with

disabilities are either non-sexual or have an exceptionally high and unhealthy libido. Either way, mainstream society rarely takes into account the sexual and reproductive rights of people with disabilities. Frequently, these rights have been seriously violated.[3]

Women and girl children with disabilities, are two to three times more susceptible to physical and sexual abuse, than women and children in non-disability population.

Persons with disabilities, like any other human beings, have their emotional and psychological needs. Marriage and companionship is one of these important needs. The Association of the people with disabilities helped, whenever possible, to arrange for marriages of its members. Mr. Chinnappan, a member of the Association of the Persons with disabilities, narrated this incident:

> Theertha Mary, a 19-year old deaf girl, was loved by Matthias, a boy of her village. When her parents realized that the girl was pregnant, they approached the boy's parents, seeking to get them married. Instead of co-operating, they sent the boy to Chennai and said that the boy was missing. We informed the police. Police took a long time to take action. Meanwhile Theertha Mary gave birth to a baby boy. Everybody thought that everything was over, but we did not give up. We did not leave the police in peace until they took action. The parents of Matthias were forced to bring him to the police station. On 29 April 2003, he came to the station and promised to marry the girl the next day. We saw to it that it was done. We could achieve this only because we were together. And now we have confidence to face any problem without depending on others .[4]

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[3] Anuradha Mohit, op.cit. p.30.

[4] *Decennial Celebrations Souvenir*, 2003, Chengalpattu,Palliagaram:

Self-reliance

Thanks to the CBR programme , they managed to set up small shops and started cattle rearing, and other programmes under the self-employment scheme. Some of them managed to get jobs in factories and other places. All these achievements, however small they may seem to be, were unthinkable a few years earlier, before the Rehabilitaiton programme at Udayam was started. CBR workers and union members made use of all the government schemes, including aids and appliances, medical and educational funds and self-employment assistance.

I was happy once again to read the Souvenir of the Decennial celebrations of Udayam Rehabilitation Centre, 2003 which reported that CBR programme had covered a population of 2,63,522 and benefited 3,249 persons with disabilities. Before they unionized, getting ID cards and aids and appliances were a Herculean task with a lot of red tape and bribery. The CBR programme, and the associations of the persons with disabilities made things a lot easier and smooth for people. A few of the numbers quoted here will give us a bird's-eye view of their achievements. 1,978 persons received their ID cards, 165 of them received wheel chairs and tricycles and 57 of them received artificial limbs and boots. I have no intention of reproducing all their achievements which will run into 2-3 pages.

Now that persons with disabilities, were encouraged to make use of the government schemes, and get the aids and appliances from the District Rehabilitation Centre, maintaining our own workshop, for the production of aids and appliances was irrelevant. So we closed the workshop on the campus. We do not need to duplicate services, which are already provided by others, either the government or other NGOs. Closing down of the services, which are no longer relevant will make available

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Udayam Rehabilitation Centre. 2003

the resources, both human and financial for more relevant and appropriate services.

In God's Good Time

After my transfer from Palliagaram, it was Sister Preethika who took the programme forward. We were lucky that the CBR coordinator Mr. Kumar, himself a person with disability, was deeply committed to his job. The efficiency of Udayam CBR Programme impressed the government so well, that when the government started the National Programme for the Rehabilitation of the Persons with Disability (NPRPD), they entrusted the NPRPD of Maduranthakam, Uthiramerur and Acharapakkam Community Development Blocks to Udayam. It meant that now the government paid 68 CBR workers and their coordinators, who were already working in the area. Udayam trained an additional 100 CBR workers and two coordinators, to meet the needs of persons with disbailities of the area, that was entrusted to them. It was a government programme, and so the government paid the salary of the staff.

With every change of the government in Tamil Nadu, the name of the CBR project keeps changing. At present the programme is called *'Puduvazhvu'* (New Life). Under this programme, Udayam Rehabilitation Centre is responsible for 135 Panchayats and 4,045 persons with disabilities, are organized into 400 and more self-help groups. All of them received their ID cards, which help them to receive various benefits from the government. 1,465 persons received appliances, including hearing aids, white canes, Braille watches, wheel chairs, crutches etc. Receiving their welfare benefits and old age pensions, were no longer a problem for these persons with disabilities. About 200 persons, with severe disability were given home based support.

Another Programme entrusted to Udayam was, Early Intervention

Centres for children below six years of age. Since this programme is meant for tiny tots with disabilities, Udayam decided to run these centres closer to the homes of the children. There are three such centres under Udayam. We were already doing this, but now the government paid the salary of the staff.

Udayam became the Nodal agency for the Rehabilitation Programmes of Kancheepuram District. Udayam was approached for the training of teachers and field level workers. Whenever there was a new rehabilitation programme to be implemented, Udayam Rehabilitation Centre was given the preference. It was hard work for the sisters, but we did not refuse any such request. It had a double benefit. Thousands of persons with disabilities in remote villages, profited from these services and these programmes provided job opportunities for the local people.

Udayam was registered under The National Trust Act for Persons with autism, cerebral palsy, mental retardation, and multiple disabilities. In every District the National Trust has a Local level Committee of three members: District Collector, a person with disability, and a NGO working in the area in the field of the above disabilities. For Kancheepuram District, Udayam Rehabilitation Centre was appointed as the member of this Local Level Committee.

Integrated Education programme was linked with the National Education Programme. Now the regular schools, where the children with disabilities were studying, allotted a room for the resource teachers. The resource teachers became full–time staff, and the government paid their salary[5]. After the struggle of about ten years, Udayam became almost self-sufficient, with the government paying the salaries of some of the special education teachers, other staff of the special school, the hostel

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[5] *New Frontiers , A History of the A.C. Mission*, Vol VII, Bangalore: Apostolic Carmel ,2008, p. 362.

and Integrated Education and CBR programme. The first fund to come from the government was the feeding grant from the State Government in the year 1999. Udayam received the feeding grant for 70 children.

Thus Udayam substantiated the definition of CBR:

> Community Based Rehabilitation is a strategy for improving service delivery, for providing more equitable opportunities and for promoting and protecting the human rights of the disabled people.

CBR is a strategy, within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.

I have given here a few details of our CBR programmes, because with a little effort on the part of Udayam Rehabilitation Centre, it was able to reach out to thousands of persons with disabilities. If we remained as a mere institution and special school, we would have served just a little over a hundred children with disabilities. Udayam was able to provide inclusive services for the persons with disability through its CBR services. I believe that CBR multiplies the effects of institutional activities, and institutional support enhances the quality of Community Based Rehabilitation services.

> If we fasten our attention on what we have, rather than on what we lack, a very little wealth is sufficient.
>
> *Francis Johnson*

14. The Great Jubilee Year and After

The Lord said to Abram, "Go from your country and your kindred and your father's house to the land that I will show you."(Genesis 12:1 **)**

"Oh! Sister, you cannot do anything here." I looked at the young girl who challenged me. "For years, this health centre has been running solely as a homeopathy clinic. What can you do here?" There was a sister who was trained in homeopathy, and she was treating the patients who came to the health centre. Perhaps the girl was right. Changes are always for the better. You are "Never too old, never too bad, never too late, never too sick to start from scratch once again," said Bikram Choudhury. The great Jubilee Year, 2000, brought about a change in my address. Now I belonged to the community of Fatimagiri in Nilambur, Malappuram District, Kerala.

Kerala has the highest literacy rate in India. In fact, its health indicators and Human Development Index are comparable to those of the most developed countries. Even when the Kerala economy had been stagnant in the 1960s and 70s, the State had been doing well, by social development indicators. This is an enigma, both for the economists and for the social scientists: a low income state with the highest social development indicators

in the country! Of course, with globalization, there is a boom of the IT sector and tourism and other service sectors, and the economy has been improving over the years. However, the social development indicators have always been higher in Kerala than than elsewhere in India.

It is the knowledge level of the people of this state, that makes them health conscious, as well as socio-politically conscious. The level of knowledge or the literacy level, is one of the indicators of the Human Development Index. However, it cannot be forgotten that there are plenty of inter-district disparities in the state, especially with regard to industrial development. Malappuram District is one of the backward districts of Kerala. The composite index for industrial development, for the different districts of Kerala, shows that Malappuram District is very poor in Industrial Development.

Kerala holds a unique position in the tribal map of India. According to the 2001 Census of India, the Scheduled Tribal population in Kerala is 3,64,189, the number of men being 1,80,169, and women1,84,020. Wayanad has the highest number of tribals (1,36,062). Idukki (50,973) and Palakkad (39,665) are the next two districts that have a large number of native tribal people. *Paniyas* are the largest tribe among the major 36 tribes. The *Cholanaikkans* found in the Nilambur forests of Malappuram District, is the most primitive tribal community of Kerala. They live in caves. Their number has been estimated to be 281.

As though to offset its backwardness, Malappuram - in particular, Nilambur *taluk* - is blessed with natural resources and scenic beauty, with its famous deep rain forests, wildlife habitats, rivers, waterfalls and teak plantations. As mentioned already, Nilambur is home to a primitive tribe of people called *Cholanaikkans or Kattunaikkans.* They are only seen in the Karulai and Chungathara forest ranges in Nilambur. They are one of the last remaining hunter- gatherer tribes of South India, living in rock shelters or

crude huts beside brooks. They speak the Cholanaikkan language, but 50% of them can interact in Malayalam. 'Chola' means deep thicket in the forest and 'naikan' means king. They are said to be warriors, migrated from Mysore, Karnataka, along with a king, but had to hide in the forests more than a century ago, due to the war in the region. They are generally of short stature, have well built strong bodies, a fair complexion, round or oval faces and curly hair.[1]

The Situational Analysis

Since I was free of the responsibilities of the health centre, I decided to look around. I was a stranger to the place, and so I sought the help of a part-time social worker. I thought of starting with the tribal people, to see whether I could do anything to help them. *Kattunaikans* are a vanishing tribe, and so they were under the special protection of the government. We had to get permission to enter these deep rain forests. We walked for miles through forests, crossed the streams and climbed the rocky hills. Some of their settlements were better off, in the sense that they could sell the forest produce, like honey and medicinal roots and leaves, to the marketing depot of the government. But there were other groups, who hardly received any substantial help for their livelihood. Many of them were sickly and malnourished. The problem was the exploitation of the forest resources by outsiders.

I met the officials of the tribal department. I spoke about the possibility of collaborating with them, especially in the field of health. They did not seem interested. They said that they had all the resources. They declined my offer, so I decided to study the problems, of persons with disabilities in Nilambur *taluk*. A base line survey was needed. The social worker, who knew the

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1 *http://www.focusonpeople.org/major_tribals_in_kerala.htm*

geographical terrain of the place, realized that it was almost an impossible task. The task would need a team of trained surveyors. People lived in far-flung areas, separated by hills, forests and rivers. Many of these remote villages were not connected by public transport. They did not even have motorable roads. We had the goodwill but lacked human and financial resources.

The social worker had an inspiration. He went to The ICDS (Integrated Child Development Services) office, Nilambur. They had just completed a survey of persons with disabilities, under the direction of Rehabilitation Council of India (RCI). The *Anganwadi* (ICDS Centres for children and pregnant women) teachers of the *taluk,* were trained in the skills required to conduct the survey. It was a survey giving the details of disabilities, with the name and address of the affected persons. Each surveyor had to survey only the families attached to the *Anganwadi,* where she was working. She was already familiar with these families and she did not have any problem covering the limited population. This increased the reliability of the survey. She affixed her name and signature to the form, provided for the purpose.

To our joy and surprise, the officers gave us the entire survey report, with the permission to make a copy of it. "We can only do the survey, but cannot provide any service. You can do something for these unfortunate people", they said. God's finger was here, once again. We analyzed the survey findings, and found that villages around Chungathara panchayat had a number of children with mental retardation. We located the *Anganwadi* teacher responsible for the area. With her help, we identified the families who had children with disabilities. The parents were very happy. "Please do something for us", they pleaded. We contacted the panchayat leaders and they promised to cooperate with us.

Out of Nothing

How do we start a programme without any resources? In

Palliagaram, I had at least an old leaky shed, to start with. Sister Preethika was trained as a special education teacher. Here, there was absolutely nothing: no place, no personnel and no funds. Nevertheless, there was an urge within me to help the children with intellectual disability. We looked around for a person to be trained as a special education teacher. No one was willing to be associated with mentally retarded persons. It was a shame to be associated with these type of people. At last ,we found a young girl who had studied up to class X. She was willing to be trained. She had neither the qualification to be trained professionally, nor had we the funds to send any one for the needed training.

Smitha, the girl whom we had recruited to be the teacher, was sent for a month's training to Udayam, Palliagaram. With the practical training she received from Sister Preethika, she returned quite confident to handle the children with disability problems. Where do we start the Special School? The social worker went around looking for a place. People were not willing to rent out a room or a house for the purpose. No one wanted the social stigma of being associated, with these uncouth and unruly children. It was already 25 March 2001. The search for a place was still on. At last, one of the Christians of the place, who was running a small hostel, told us that the hostel would be free for two months. We could use one of the rooms just for two months. We accepted the offer.

The school was inaugurated on 2 April 2001. To start with, there were six children, all from the same village, an inexperienced teacher and a temporarily rented room. It was a Day School. Since there was no vehicle, it was impossible for children from other villages to be brought to the school. All the same, the school had started. It was named after Mother Veronica, the founder of the Apostolic Carmel. I was sure that Mother Veronica would look after the school and its progress. And she did. The provincial superior sent Sister Beatressa, for training in Special Education for the mentally challenged. In April 2002, I

had to leave for Bangalore. Smitha bravely continued the school, until Sister Beatressa took charge of it. The school had to shift to four different rented houses, before it was established on its own premises. For nearly three years, Sister Beatressa was the only trained teacher. I kept in touch with her and guided her in all her activities and decisions.

The number of children increased year after year. Sister Rosy Joseph, the Provincial Superior, bought a small plot of land in Thalanji village for the school. Our friends and benefactors helped to construct the building. A few classrooms were got ready and on 15 September 2004, the school shifted to its own premises. The building was completed and the inauguration took place on 2 February 2006. Sister Beatressa steadied the school during its first ten years of existence. Her persistence and perseverance resulted in the children getting scholarship funds from Panchayats. Nor did she rest, before the school was put on the list of the state government, as eligible for a grant. In 2011, the school started receiving the government fund for the salary of some of the staff of the school.

As in Udayam, a well equipped physiotherapy section was part of the special school. The children were systematically trained. With an individualized education programme, these mentally challenged children progressed rapidly. The severely retarded group of children were given the stimulation and care that they needed. The teachers could narrate any number of examples of children, who responded to their carefully planned training. I give here only a few examples from the school report.

> Ammen, a teenager, had been kept closed up in his grandmother's house, without any outside contact. Now that they have brought him to the school, he is beginning to enjoy being with others and is learning social skills.
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> Hisan, a severely retarded autistic seven year old, was on

bottle feed. Within three months, the child was trained to be off the bottle feed and started taking solid food, and that by himself.

As a result of the persistent effort of the teachers, every year 2 or 3 students are able to take the exams of various classes, conducted by the Literacy Mission of Kerala. Three of them were able to answer the Class X examination.

Sister Alphonsa John, who took over from Sister Beatressa, in 2011, continues with the same enthusiasm. At present, about eighty five boys and girls, with intellectual disability are receiving training and education in Mother Veronica Special School. The children excel in sports and cultural activities, which are regularly organized for them.

Come and See Where We Live

Now to go back to the year 2000: while the search for personnel and place for the special school had been going on, I had been thinking also of economically weaker groups, and their needs. It was a Sunday evening, when some women, as though from nowhere, turned up at the convent door and said, "Please come and see where we live." It looked as though the Lord was waiting to see, whether we would respond to people in any kind of need. We went to see the village, from where these women had come. We had to cross lonely forest areas and climb hills, before we could reach Perambuthur and its neighbouring villages. The private agencies and NGOs, including the Church Social Service Societies, did not reach these remote villages. They were left on their own to manage their lives in the way they could.

For me, it was an unimaginable situation. Their huts had no walls and the floor was mud plastered. In this agriculturally conscious state, the percentage of people living below the poverty line may be lower than, those in other states of India. Yet, it was very clear

that the new economic policy and liberalization had affected this tiny state in no small measure. The percentage of poor had increased from about 12% of the population to 16%, within the last eight to ten years. This means, that about five million people of Kerala live a hand to mouth existence. That was the reality that I saw in the villages I visited.

We started with five villages. The village chose their women representatives, whom we trained as health workers. Now, it was their responsibility to organize the women of their respective villages into Self-Help Groups (SHGs). We provided the training needed for these groups. They started their regular meetings and saving schemes. We pitched in with the income generation and housing schemes. They were the decision makers. The SHGs drew up the criteria for choosing the beneficiaries. During our visits to the villages, we checked the list of beneficiaries and found that they were selected, without any bias or personal preferences.

We are Responsible for Our Future

If these women could live in these harsh circumstances and still have hope in their hearts, they were surely people of strength and stamina. We tapped the resilience of these women. The donor agencies, who helped with housing and income generation projects, told the women that they were giving them the money as a loan, and the women had to repay the loan in small instalments over a few years. The amount received as repayment would be used for the next group of beneficiaries. However, they were given a subsidy of 50% in the first year, and then 20% for the next two years. The women decided that they would repay the loan with 1% interest, since the revolving fund was going to be used for the members of the SHG.

They contributed labour for the house construction. They supervised the construction of their own houses. This ensured good quality houses for the money spent. In case of income

generation projects too, women made sure of the value of the product they were receiving for their money. There were no middlemen. I was happy, when the women said, that they would do their own purchasing. Besides cattle rearing, the women took up sericulture, piggery, vegetable cultivation, rearing of quails and so on. To our surprise, the women were prompt in repaying the loan. They were accountable to the group. Moreover, the next group of beneficiaries was waiting for houses and other schemes, so there was no question of defaulting. The refund, thus received was deposited in the joint account of the SHG. The sisters and the social worker supervised the programme, as they were accountable to the donor agency. However, the actual implementation of the programme was in the hands of the women themselves.

I was with them only for a year. The following year, I visited them every 2 or 3 months, in order to support and guide the project. The social worker was a sincere and hardworking person. Then, Sister Renée took charge of the programme. We kept in contact and made sure that the project was implemented in accordance with the original objectives of self-reliance and self-governance. In her annual report of 2008, Sister Renée summarized the 'Utilisation and Repayment of the Revolving Fund' of the past six years. They had to repay the full amount of the loan with 1% interest. During this period, the revolving fund of Rs. 24,13,250/- was taken as loan by 314 members. Rs. 21,36,270/- was repaid. The repayment rate was above 90%. The repayment of the loan taken for house construction and repairs, would take a longer time. The loans were taken for major house repairs, for toilet construction, for education of their children, for income generation schemes, for marriage and for medical expenditure.

Sister Renée writes,

> You will be happy to know that the women are using the fund intelligently. They are also keen to form a few more

> SHGs, so that some more women get the advantage of being members of the SHGs...The Credit goes to the poor ordinary village women. Their integrity and concern for those, who are as much in need of help as they are, is to be admired. They seem to have understood that the Revolving Fund can be better utilized, if those who take loans are regular in repaying it, so that others too get the benefit of it.

I was delighted when Sister Renée further wrote, "The SHGs do not think only of themselves. They have decided to help at least one family every year, living in dire circumstances, even if they do not belong to their group."

The Way Forward

These SHG groups - there are twenty of them now - are also active members of their respective panchayats, so they received loans from the panchayat, with subsidies of a bigger margin. This again helped them to improve their economic status. In their groups, they fixed a minimum rate of interest. Within a period of three years, they had mobilized a sum of about Rs.4,00,000/-. They decided to make use of the interest accrued from this amount, to help any destitute family in need of help. So far, they have helped six families, who had no houses at all, with house construction. The women motivated church members, and other relatively rich folk to contribute to the cause, so that decent houses could be built for the poor. Since these poor people were really destitute, because of unemployment, poor medical conditions and other problems of the families, they were not expected to pay back the money. The houses were purely gratuitous gifts from the SHG members to these families.

The interest of this capital was also utilized for their meetings, study classes and input sessions on various topics of interest to them. They invited resource persons from the agricultural

department, sericulture, village industries, bank officials and so on. They saw to it that all their children went to school. The women proudly reported in 2007, that all the 20 girl students who had passed Class X examination were pursuing higher studies. They were able to give some cash incentives to the students who did well in their studies. It was not easy for the students, from these villages to go to schools and colleges. They had to trudge long distances, as these villages were not connected with any transport facilities. The women did well to encourage their daughters to pursue higher studies.

The donor agency contributed money in instalments, only for the first three years, when the SHGs built 60 houses with toilets, another 65 toilets for those who did not have toilets for their houses, five wells for those who required them. Ninety families received assistance for income generation schemes. All of them repaid the money, according to the conditions given to them. Now, the project has been going on for ten years, without any assistance from outside. These women and their families are free, not only from moneylenders, but also from donor agencies.

Social work need not make people dependent on us. It is important to move away from charity, and even from development models, to empowering models. We can say that we have succeeded in our purpose the day people say, "We have done it for ourselves". I am happy that these women are doing it for themselves.

> There is nothing fixed, nothing eternal, nothing 'sanatan'; everything is changing, change is the law of life for individuals as well as for society. In a changing society there must be constant revolution of old values.
>
> *Dr. B.R. Ambedkar*

15. Slums and Street People

"Why does he eat with tax collectors and sinners?" When Jesus heard this, he said to them, "Those who are well have no need of a physician, but those who are sick; I have come not to call the righteous but sinners." (Mark 2:16-17)

According to UN-HABITAT, India is home to 63% of all slum dwellers in South Asia. This amounts to 170 million people, 17% of the world's slum dwellers. The Universal Declaration of Human Rights, Article 25, states,

> Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

According to the census of India, 2001, a total of 52.4 million people are living in slums in 1,743 towns, which constitute 23.5% of the population in these towns. However, the Census Report admits that many states did not include smaller towns in the survey. Nor did some of the smaller states conduct the slum

survey as required. According to the UN Report of 2001, India's urban slum population is estimated to be 158.42 million[1] .

It is also a known fact, that many homeless people are not counted in the census and slum surveys, because they are pavement dwellers and they seek shelter there only for the night. The estimate given for 2010 was about 93 million, as the count of homeless people in India. As India continues to grow in economic stature, there is much debate over the country's ability to tackle poverty and urban homelessness.

Releasing the data of Census 2011 on housing, household amenities and assets, Registrar General and Census Commissioner C. Chandramouli said, that the lack of sanitary facilities continues to be a big concern for the country. Only 46.9% of the total households have toilet facilities. (*The Hindu* 14.3.2012). Then one can very well imagine the condition of homeless people. The Slum Clearance Board in Chennai published their findings in 2005 : a survey of 3.2 undeclared slums in Chennai revealed that only 29% had access to individual toilets or pit latrines. The rest of the families used public toilets or had no access to toilets at all. Moreover, "The public toilets were poorly maintained, had frequent blockages, and lacked water and electricity." Naturally, people did not use these stinking toilets.

The Health Status of the Urban Poor

With such a sordid state of living conditions, and inadequate supply of drinking water and toilet facilities, we cannot expect the health conditions of the slum population to improve. The national urban health indicators, which are an average of the health status of the total urban population, mask the great divide

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1 "Report of the Committee on Slum Statistics/ Census ,Government of India" , New Delhi: Ministry for Housing and Urban Poverty Alleviation, National Buildings Organization, 2010.

between the urban rich and the urban poor. In 2007, Dr. Nihar Ranjan Ray and Dr. Nayan Makwana , of The Indian Institute of Public Health, Gandhinagar, published their findings in 'Health of the Urban Poor in India.' According to them, the percentage of children receiving all immunization is only 42.9%, 56.8% children are underweight and only 47.7% pregnant women receive three recommended antenatal visits. The Institute of Social Studies Trust gave the reason for such a sorry state of health of the slum population.

> The long queues and impolite manner in which they are spoken to, discourage the poor from turning to the government services for medical relief. The Maternal and Child dispensary is located at walking distance from slum clusters, but the availability of doctors, medicines and chances of treatment here is erratic. Seldom are the doctors or medicines available.[2]

These findings were corroborated by the draft text prepared for discussion on 'National Urban Health Mission.' This paper mentioned that,

> Despite the supposed proximity of the urban poor to urban health facilities, their access to them is severely restricted. This is on account of their being 'crowded out' because of the inadequacy of the urban public health delivery system. Ineffective outreach and the weak referral system also limits the access of the urban poor.[3]

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[2] Suchi Pande, "Background note on health in urban slums in Delhi." *Ensuring public accountability through community action 2005,* New Delhi: Institute of Social Studies Trust. p 9.
http://www.isst-india.org/PDF.Health%

[3] *National Urban Health Mission, Draft for circulation*, (2008-2012), New Delhi:Urban Health Division, Ministry of Health and Family Welfare

These stories are not of one slum or of one state. Afshan Yasmeen reported on 1 May 2012, in *The Hindu*: "Bangalore with its slew of corporate hospitals vying for foreign patients may be one of the top health tourism destinations on earth. However, for those living in the 500 plus slums here, even basic state sponsored health care is a mirage." The reporter went on to give examples of women giving birth in the public parks and on footpaths of the city, and dying of bleeding and other complications of delivery.

Promises not Kept

The Ministry of Health and Family Welfare, Government of India, is very well aware that it needs to address the health concerns of the urban poor. Thus, during the Eleventh Five Year Plan, the Government proposed the initiation of The National Urban Health Mission (NUHM), which was supposed to be modelled on the principles of The National Rural Health Mission. Instead of ASHA, NUHM was to have Urban Social Health Activist (USHA) as the community representative. However, at the time of writing this, the Programme seems to be stuck in the muddle of bureaucracy. Hopefully, it will take wings without delay. As things stand, no remedy is in view yet, for improving the health and nutritional status of the urban poor.

> Despite its promise of urban health as a thrust area, the Eleventh Plan did not provide for the NUHM in terms of budgetary support. The outcome of the series of hearings, conducted by The National Human Rights Commission (NHRC) in 2004-2005, in collaboration with Jan Swasthya Abhiyan (JSA), in the context of denial of health care, is nearly forgotten.[4]

Government of India. p.3
http://www.uhrc.in/downloads/reports/NUHM.draft.pdf.

[4] Rajib Dasgupta, Ramilla Bisht, "The Missing Mission in Health," *Economic and Political weekly*, Vol. XLV, NO.6 (2010):p.18.

We do not give up hope. The World Health Assembly, which is the decision making body of The World Health Organization, adopted the concept of Universal Health Coverage (UHC) in 2005. According to the Assembly, UHC is imperative for all countries, so that the gains of public health programmes can be consolidated and made available to all the people. The editorial of the *Hindu* 31 May 2012, gives us a glimpse of hope:

> India's nascent effort to achieve UHC will take shape during the Twelfth Plan and it will do well to learn from global examples...the Thai reform programme stands out as a bold initiative because it was undertaken in the wake of the Asian financial crisis of 1997. It progressed on equity objectives by adopting a tax-funded model, strengthening primary care and disease prevention, and crucially, capping provider payments to regulate costs. India faces a challenge on these very issues with rising costs of private care and insurance payments that few can afford. Fortunately, it has its own remedial blueprint prepared by the High Level Expert Group (HLEG) on UHC instituted by the Planning Commission.

Even though we do not despair, past experiences of implementation of many of the government programmes, make us wary of this one as well. India's public spending on health, ranks among the lowest in the world. With serious financial restrictions imposed on this programme, will HLEG recommendations take wing? What about the possibility of the political and industrial lobbies hoodwinking the people, and twisting the programme to fit into their profit-generating market approach?[5]

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[5] Gita Sen, "Universal Health Coverage in India, a Long and Winding Road," *Economic and Political weekly*,XLVII,No.8, (2012):p.49.

The Story of Kantha

In 2002, I was back in Bangalore. It was about 9 p.m. I was returning from the super speciality hospital, which is very close to our convent. One of our sisters had to be admitted there for an emergency situation. It was a dark and cold night. A feeble cry *'Amma, Amma'*, came from close by. I had heard that drug addicts and rag pickers lived on the pavement, adjacent to the convent and I was afraid. I walked fast and reached the convent, but that cry kept disturbing me. I sent our watchman to the group of people living on the pavement, to inquire what was happening there. Whatever the need was, they could come to me early next morning. The sight that greeted me in the morning was pathetic. Kantha, a twenty seven-year-old woman, was severely breathless. She could not stand upright, and her husband supported her. They were rag pickers and, as pavement dwellers, they were clothed in old shabby, smelly clothes. I could sense that they were drug addicts too. They had four small children and the youngest was one year old.

I quickly examined her. A provisional diagnosis of bilateral tuberculosis was made. We have a crèche for slum children on our campus. The woman and the children were given a bath and a change of clothes. One of our helpers, accompanied Kantha to the government hospital, which was only five minutes' walking distance. Kantha ,of course, could not walk, so we sent her in a three wheeler to the hospital. Being pavement dwellers, the family did not have the BPL card, and so they were expected to pay for all the medical services. However, this time we were there to pay for the X-ray and other tests. The diagnosis of bilateral tuberculosis was confirmed. They were told to go to The National Institute of Tuberculosis for the treatment and so they came back to the convent.

Kantha was too ill and the family was too poor and illiterate.

They would get nowhere with all the formalities of the hospital, so I decided to accompany them. There were so many forms to be filled in, before Kantha could be seen in the OPD. I found it the height of injustice, when one of the senior doctors asked me why I had brought this patient. "You should have allowed her to die. She must be suffering from HIV," he told me. I stared at him in anger and so, he did not continue his argument. She needed sputum tests, and other investigations to be done before she could be admitted. "The patient needs to pay for all these tests," they said. I was angry at the irony of this situation. Finally, someone suggested, that I go to the financial administrator. He was sympathetic and understood the situation. So, he certified that Kantha was eligible for free treatment. All this took a long time, 3 to 4 hours. I was getting anxious about Kantha's condition. Seeing my despair, someone brought a wheelchair for her. Finally, she was admitted. In spite of being certified as a free patient, she was being harassed for payment. Hearing this, I went once again to the hospital, and was quite stern with the doctors. After that, she was left in peace.

It took three months in the hospital for her condition to improve. After that, I took the responsibility of getting the medicines for her under the DOTS (Directly Observed Treatment-Short course) programme. I must add here that Kantha's blood tests showed that she was HIV negative. Her children were cared for in our crèche, and the older children were admitted in the school on the campus. With regular medication, Kantha fully recovered. I had been contemplating a way of getting some cheap housing, in a suburban location, for some of these pavement dwellers. Then, on a fatal day, I heard that, under the cleaning up operation of the Corporation, Kantha and her family, and the whole group of pavement dwellers of that particular area were evacuated from the pavement. I lost touch with them.

This incident always saddens me. I have narrated it here, because

it is a concrete example, of the lives of millions of homeless in urban India. They live under the constant threat of eviction and police harassment. They are an eyesore to the rich. So, at times, they are rounded up and taken to beggars' homes, and kept almost as prisoners. They are without address or ID cards. They are considered as criminals and intruders. They are almost non-existent in the government records. Without BPL cards, these pavement dwellers get no benefit of government schemes, including that of food grains under the Public Distribution System(PDS). Moreover, we have seen how people like Kantha are treated in the government hospitals. Are they lesser human beings?

> Dispossession of the poor and deepening forms of inequality has been a central feature of the contemporary re-envisioning of urban landscapes across the world... Research in Indian cities such as Mumbai and Delhi has shown that these processes have been put into motion by evicting poorer and less enfranchised inhabitants such as pavement dwellers, slum dwellers and street vendors through systematically labelling them as, 'encroachers' and 'illegal' as well as through legal discourses of a 'nuisance'.[6]

The Sisters and the Slums

Bangalore city, hailed earlier as the garden city and the pensioners' paradise of India, transformed itself , first into IT hub, then a concrete jungle of flats and IT companies, and now is fast becoming a place of homelessness and slum dwellers. It

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6 Renu Desai, " Governing the Urban Poor: Riverfront Development, Slum Resettlement and the Politics of Inclusion in Ahmedabad," *Economic and Political Weekly*, Vol. XLVII,NO.2,(2012):p.50

is estimated that there are more than 18,000 homeless people in Bangalore city. With the influx of more and more people into the city, the number of homeless people is bound to increase. The NGOs and the slum leaders of the city of Bangalore say, that there are about one thousand slums in the city.

From the first year of the foundation of the convent in Bangalore, our sisters started teaching in a primary school in the slum area. The school was in the slum itself and the school belonged to the diocese (church). As soon as the sisters began teaching in the school, the number of children increased, and the tiny building could not accommodate all the children. Our sisters worked hard with these unruly and unkempt children, and the boys and girls were won over by the love and affection of the sisters. To combat malnutrition in the children, the sisters started looking after infants as tiny as six months of age. The crèche benefitted about one hundred and fifty tiny tots.

Gradually, the management of the school was given over to the convent. The sisters upgraded the school to high school level, and the school was shifted to the convent campus. After the age of five, the children from the crèche could continue their education on the campus itself. Many of the boys and girls, who studied in this vernacular school, are today well placed in government services and other jobs. They are ever grateful for the free education they received in the school. They show their gratitude by offering their services for free coaching classes, that we organize for the students of Class X.

Now that I was in Bangalore, I looked around to see whether I could do anything for the grown-ups in the slums. The sisters were doing a marvellous job with the children in the crèche and in the school. There were numerous NGOs working in the slums in various capacities. What else could I do? We had a meeting of the women from the slums. "You do not need to do anything for us women. Do something for our men. God will bless you if

you cure them of their drinking habit", was their plea. I assured them that I would think it over, and do whatever I could about this problem.

A Public Health Problem

Dr Vivek Benegal, in his article, 'India: Alcohol and Public Health', says , "A recent National Household Survey of Drug Use in the country, the only systematic effort to document the nation-wide prevalence of drug use, recorded alcohol use in only 21% of adult males." Globalization, and its consequent economic liberalization, has caused an attitudinal shift regarding the consumption of alcohol, from being rare and abnormal to being commonplace and normal. What is more, is the fact that alcohol consumption is promoted indirectly by the state governments, by the liberal licensing system, because most states derive 15-20% of their revenue from taxation on alcohol, which is the second largest source of the states' exchequers, after sales tax. Further, the alcoholic beverage industry visibly influences the political process, with contributions to political parties and in the form of inducements to voters during elections. All these factors have contributed to significant lowering of age at initiation of drinking. Alcohol sales have registered a steady growth rate of 7-8% in the past three years.[7]

No wonder then, that morbidity due to alcohol consumption is mounting rapidly. Alcohol-related problems account for over a fifth of hospital admissions, but are underrated by primary care physicians. Alcohol misuse, has been implicated in over 20% of traumatic brain injuries and 60% of all injuries reporting to emergency rooms. It has a disproportionately high association

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[7] Vivek Benegal, "India: Alcohol and public health," The Globe, 2 (2005) London: The Society, National Addiction Centre, 4 Windsor Walk. www.ias.org.uk/resources/publications/theglobe

with deliberate self harm, domestic violence, high risk sexual behaviour, HIV infection, tuberculosis, oesophageal cancer, liver disease and duodenal ulcer[8].

The above discussion shows that alcohol consumption is not confined to one social class or caste. It is widely prevalent among all sections of the people, irrespective of class or caste, urban or rural. Nonetheless, people engaged in hard physical labour tend to seek the comfort and escape mechanism, derived from heavy alcohol consumption. This drives them into further poverty. Thus, alcohol misuse and poverty form a vicious circle: the addictive behaviour often causes people to sell their assets to meet the medical expenses, and the poverty and hard labour drives them into a heavy drinking pattern.

The Need for a Definite Indian Alcohol Policy

The Constitution of India, among The Directive Principles of State Policy, Article 47, says:

> The state shall regard the raising of the level of nutrition and standard of living of its people as among its primary duties and in particular, the state shall endeavour to bring about prohibition of the use except for medicinal purposes of intoxicating drinks and of drugs which are injurious to health.

While there is no doubt, that the addiction to alcohol is becoming a public health problem, the state governments are unwilling to curb this problem, because alcohol is a significant contributor to government revenues in many states. The report of The Seventh Conference of The All-India Democratic Women's Association (AIDWA) stated that the alcohol industry generates an estimated

[8] ibid.

Rs. 16,000 crores a year. The policy of granting licences for vending by states has been so generous that, there are more such vendors than schools and public health centres in many states.

In Tamil Nadu, for example, Tamil Nadu State Marketing Corporation (TASMAC) ,a company owned by the government of Tamil Nadu , has a monopoly over wholesale and retail vending of alcohol .It controls the Indian Made Foreign Liquor (IMFL) trade in the State. The annual tax revenue for the financial years 2009-10 and 2010-11 was Rs. 12,491 and 14,965 crores, respectively. Besides the tax revenue, the company also makes money, by selling annual licenses to run bars in its retail outlets. The write-up on the history and growth of TASMAC says, that revenue from alcohol sales constitutes nearly half of the State's annual tax revenues.[9] It is not very different in other states. The alcohol sale generates one third of annual revenue in Punjab. Kerala, with all its achievements in social indicators, has also the first place in per capita consumption of alcohol!

The consequence of such free licensing of alcohol outlets by the state governments is encouraging youth to indulge in alcohol drinking at an early age. Monica Arora, the Programme Manager of Hriday/Shan, wrote in her article titled, 'Alcohol in India':

> An important aspect of policy is to delay initiation among youth. One way of doing this is to enforce age limits. It has been shown that an increase in the age of legal drinking from 18 years to 21 years achieves nearly 60% of the effect of prohibition on alcohol consumption.

The World Health Organization Regional Office (WHO–SEARO) issued a document on the need for Alcohol Policy Intervention

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[9] Tamil Nadu State Marketing Corporation, en.wikipedia.org/wiki/Tamil_Nadu_State_Marketing_Corporation

in India. This document says that there is an urgent need for the policy intervention in India, because of increasing focus of the Alcohol Industry in the country and increasing alcohol use in the region.

Drunken Men on the Convent Campus

The convent campus, with the generalate headquarters, and six institutions, was well laid out and kept immaculately clean. Moreover, we had the resident students and working women on the campus. I was thinking of conducting a residential camp, of ten days for the alcoholics from the slums. Is it safe, first of all, to bring these alcoholic men to this 'all women' campus? Will anyone agree with the idea of conducting a camp on the campus, for these dirty, alcohol-stinking poor men from the slums? They needed an enclosed place, because they could be violent during the initial days, with withdrawal symptoms and other medical conditions.

I was silent and thoughtful. Sister Jyotsna, the Principal of the Kannada Higher Primary School, asked me what the matter was. I shared with her my anxieties and, especially, the need for a secluded place. She offered the ground floor of her school, which could be locked in case of need. She was happy with the proposed camp. The children of her school, were all from the slums, and alcohol addiction was playing havoc in their families. Sister Vincent, the then Superior General of the Congregation, encouraged me to proceed with the plans, and made available the funds needed for the programme.

From then on, things moved fast. Sister Adelcia, another doctor of the Congregation, had the experience of conducting camps, and treating the alcoholics of the villages of Bidar in North Karnataka. I requested her and her social worker to help us organize the camp, so that we could learn the method from them. They

willingly agreed. Meanwhile, Sister Jyotsna did the spade work of contacting the mothers of her students. She also explained the purpose of the camp to the children. They were very happy to know, that their fathers would be able to give up drinking and lead normal lives, so the children were very cooperative.

10 January 2004, was the historic day, when twenty five heavily drunk men from the slums, were brought to the convent campus by their wives and children. It was a frightening sight. Some of them were outright violent. Many men were wobbling in their drunken state and had to be carried. The presence of Sister Adelcia and her social worker soothed the situation. They knew how to handle them. The names were registered and the camp for the alcohol addicts was begun.

After 2 or 3 days' stay in the camp, the withdrawal symptoms gradually subsided; the men became as meek as lambs. A regular timetable was planned for them, starting the day with yoga and prayer, followed by various duties of cleaning their room and the surroundings. Personal hygiene and cleanliness were insisted upon. Classes were conducted on topics like, what alcoholism is, what it does to them as individuals, family and society, to their work and health and so on. They shared their problems in small groups, and participated in question and answer sessions. Counselling sessions, and medical check-ups were interspersed during the day. In the evening, they enjoyed playing cricket and other games. Their wives were invited on one of the days of the camp. They were given tips, which would be helpful in dealing with their husbands when they returned home.

This camp was not based on a medical model. Counselling and the support system were the mainstay of the camp. They were made to understand, that their addiction was a disease and that even a drop of alcohol would cause their disease to flare up, and their condition would be worse than in the past. They needed the support, not only of their family, but of one another, so after

the ten days' camp was over, they needed to come daily at 7 p.m. and meet and share their experiences. They and their families were made aware, that relapse was quite common; but they must continue coming for the daily meeting.

'Matha' will look after Us

They began coming for the follow-up meetings. The men were so happy, that they had a respectable place to meet and share their problems. Whatever their religion, they were very particular to pray at the grotto of our Lady of Lourdes. "It is the 'Matha' who is looking after us", they said. Whenever I was in Bangalore, I was with them for their follow-up meetings. As one of the general councillors of the congregation, my responsibility was for the whole congregation, and so I had to be often away from Bangalore. Sister Jyotsna assumed the responsibility for the camp and for the group. Once the sisters of the community understood the purpose of this work, all of them supported the programme.

The improvement in the behavior of these men inspired others, to seek help for the alcoholic problems in their own families. The demand was so great, that in the first year, we had to conduct two camps. Then, it became an annual feature. Luckily, the news of the sisters working with the alcoholics from the slums reached the ears of AA (Alcoholics Anonymous) members of the Bangalore group. "We should have done this and not you," they said. Initially, they came as resource persons and shared their experiences with the camp members. From the fourth camp onwards, AA volunteers were there as full-timers during the camp, both day and night. This relieved our tension of managing the alcoholics during the first few nights of the camp, when some of them would be violent due to withdrawal symptoms.

The number of participants of each succeeding camp continued to increase. Finally, during the last four camps, we had to restrict

the number to one hundred and twenty five. The follow-up meetings were planned in different places closer to their homes. People from the slums, close to the convent continued to come to our campus. We do not have a board displaying the de-addiciton programme, but the members named it, 'Carmel De-addiction Centre'. So far, we have conducted ten camps for the alcoholics. A total of about eight hundred men have participated in these camps.

Unlike other diseases, in alcoholics the relapse rate is quite high. So, we need patience, as well as humility to receive them again and again for follow-up meetings, as well as for the camps. Once the Bangalore AA was associated with our programme, the follow-up meetings were conducted only among the alcoholics. They follow their twelve-point programme. Forgiveness is one of the points insisted on, in these meetings. They will never refuse anyone wanting to attend the meeting.

The complete cure in our centre may be about 30%. Every year, ten to twelve of them celebrate the 'First Birthday' of their successful 'dry' year. Another 60% keep coming for the follow-up meetings. They relapse and they come back. Work with alcoholics is not like working with the students, not even like working with women and the persons with disabilities. Here, success rate is quite low.

The low success rate need not discourage us. Velu was addicted to alcohol to an extreme degree. He was a daily labourer, and all that he earned went into drinking. The family was in ruin. His health deteriorated, and on most of the days he was not able to go to work. His wife was a patient, with heart problems and she was anxious and sad. They had five children, and they survived because of the midday meal that they got in the school.

Fortunately, his wife and his friends managed to bring him to the camp. After three or four days in the camp, he came to his

senses. His children met him, and their smiling innocent faces and their affection touched his heart. He was determined to change. In fact, it used to be said in his slum that, if Velu could give up drinking, then anyone could. Velu did change, as did many of his friends.

His determination to lead a dignified life, overcame his urge to drink. He did relapse a few times, but his wife and children saw that he came for the follow-up meetings, and that he got the support of the group. The family was with him. Today, he is a hard working, good husband and a loving father. The children are ever grateful for the camp, that we conduct for the alcoholics.

We are happy that we have provided a support system for these despairing men and their families. When I see the joy on the faces of the children, whose fathers have been cured of alcohol addiction, I feel that the effort made for this cause has been worthwhile.

> Never worry about numbers.
> Help one person at a time and
> always start with the person nearest you.
>
> *Mother Teresa*

Conclusion

I have shared with my readers a significant part of my life journey; a tortuous journey through the healing ministry, which made me understand its wider implications; a winding path, that led me to social and even political action. In this process, I learnt that the rights-based approach is the right approach, when working for the people and with the people, especially when they are marginalized groups.

As I look back at my years in the healing ministry, I am glad that I was able to leave a trail of a Comprehensive Health Programme, with its preventive, promotive, curative and rehabilitative aspects. I do not claim that everything on this journey was perfect and faultless. There were pitfalls, obstacles and even detours. Nevertheless, I am happy that, despite the limitations, personal or otherwise, I was able to move forward, as a woman and as a religious, towards my goal. I am glad that I was able to translate my innate aspirations and dreams into practice, in my living and working with the people. The remoteness of the place and the paucity of resources did not deter me. The vision constantly beckoned me and I followed.

I was fortunate that the superiors and the sisters of the community were ready to carry on these activities, whenever I had to move out to other places and to other fields of work. After all, it is the Lord's work and it is he who hears the cry of his people. Ours it is to listen to the small, inner voice and to respond to it with magnanimity of spirit.

We are more than one lakh religious women in India. If all of us shared our stories, of walking with people of different categories, it would strengthen our solidarity, and provide the network and support system, sorely needed among us. The Church in India would be the richer for it.

I am not presenting a finished product. I continue to dream; the journey continues. New challenges explode on the horizon. I hope a new generation of dreamers and actors is on the rise.

> Commitment leads to action.
> Action brings your dream closer.
>
> *Marcia Wieder*

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Sr Agnesita A.C. is a Doctor, Religious Sister, trained by St. John's Medical College in Bangalore. She has worked in different parts of the country in the field of medical and social work.

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Through very moving stories and case studies she has brought together a deep humanism and a professional perspective that is willing to go beyond the bio-medicalized hospital model...I would recommend this book to all those who wish to become fellow travelers on the long road to Health for All. For those who are already on this journey the book will be an invitation to reflect and recharge one's battery to continue the journey.

Dr. Ravi Narayan
Community Health Advisor,
Society for Community Health, Awareness, Research and Action (SOCHARA),
Bangalore.

I am grateful to Dr. Sr. Agnesita for venturing into writing "Health for All: A Right and A Possibility", to highlight the woefully inadequate and misplaced health-care facilities in our country. Her contention that something can be done in this area OUT OF NOTHING is so true.

Bishop Percival Fernadez
Emeritus Auxiliary Bishop of Bombay

Sr. Dr. Agnesita A.C. has fought a good fight, to make Health for All , a Right and a Possibility by her prophetic and proactive presence and service among the exploited and the less privileged. May ... her rich experiences inspire, enthuse and energize every committed healer to reach out to the unreached with health and wholeness.

Sr. Dr. Lucian SCC
President, Sister Doctors Forum of India.

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